

# Meanings of social exclusion and inclusion in relation to older people with dementia in care homes.

Ruth Bartlett

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## **ABSTRACT**

This thesis explores the meaning of social exclusion in relation to older people with dementia in care homes. Its central objective is to identify the main influences shaping meanings of exclusion and inclusion in this context, and to understand how these influences are personally encountered and countered. The social model of disability underpins and directs the investigation as this framework already offers a convincing account of what social exclusion and inclusion means to people with disabilities. A secondary objective is to therefore evaluate the relevance of this model to understanding the position of this group of people in this setting.

A variety of qualitative methods are used to provide a subjectively rich and diverse account of meanings of social exclusion and inclusion in this particular context. Influences shaping meanings of exclusion and inclusion are primarily analysed and explored through the accounts of care home life given by individuals with dementia, their relatives, other residents, home care managers and care workers. In addition, individual care records and organisational policy and publicity are analysed for cultural representations of dementia and disability.

It is argued in this thesis that in relation to the people and places involved in this study the core meaning of social exclusion is loss of identity. The main influences leading to this conclusion were social, psychological, economic, organisational and biological in nature and form. In addition, it is argued that while the social model of disability usefully politicises the position of older people with dementia in care homes, the binary opposition on which it is based, namely medical/social, is too simplistic for understanding the complex and fluid relationships, that the people with dementia involved in this study, had with their social world.

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### **Collaboration with larger project:**

For the first two years, this study was carried out as part of a larger project. This meant I gained formal ethics approval for this study, gained access to study sites and most participants and collected data as part of a small project team. All other activities, including data analysis, were carried out entirely independently of the larger project. The full extent of the collaboration is described in section 4.4 of this thesis.

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## **PART ONE**

### **Introduction and background to the study**

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The following introductory chapters outline the principle areas of interest for this study. Chapter one provides a basic orientation to the thesis including a short autobiographical account, which positions me as the researcher and makes explicit my background as a mental health nurse with professional experience of nursing older people with dementia. Chapter two serves as the main justification for the study and highlights where the gaps are in our understanding of social exclusion, particularly as it relates to older people with dementia living in residential care homes. Lastly, chapter three introduces and critically reviews the principles underlying what has become known as the social model of disability. This area of research is more commonly associated with understanding the situation of younger people, who are physically disabled, but which this study examines for its relevance in the context of older people with dementia in care homes. Modern theoretical developments in the social model of disability are also evaluated. These chapters combine to provide the intellectual justification for this study, and to inform the methodology.

# **CHAPTER ONE**

## **Introduction to the study**

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### **1.1 Introduction**

This thesis is about social exclusion, and in particular, about the influences shaping meanings of social exclusion in relation to older people with dementia in care homes. The central objective of this opening chapter is to explain in broad terms why the exploration of this particular phenomenon and social situation was so important to study at this time, and to reflexively detail how and why I decided to study them. A secondary aim of the chapter is to orientate the reader to the content and structure of the thesis, including the research questions which underpinned and directed it.

### **1.2 Focus of the study**

This is a sociological thesis. At the heart of the enquiry is a basic interest in power and power relations between individuals and society (Charon, 1995). The particular relational dynamic that this study is interested in is the power that some individuals and communities have to exclude others (Byrne, 2000). Meanings of social exclusion and inclusion are explored in this study through the experiences of a sample group of older people with dementia in care homes. The different reasons for exploring meanings of exclusion and inclusion in relation to this particular social group and living arrangement are introduced in section 1.4 of this thesis and comprehensively explained in Chapter 2. One rationale underpins them all and that is, that growing old, becoming ill with this condition and moving into a care home are all transitions when, from a sociological and political perspective, the mechanisms and agents of power (such as doctors, family, young professionals) have the potential to act with greatest influence and control (Fox, 1993; Lupton, 1997). It seems reasonable to me to suppose that the combination of these events

intensifies, and thereby makes more discernable, meanings of exclusion. Essentially, this is why the central focus of this study is this particular social group and setting.

A focus upon the influences shaping meanings of exclusion and inclusion in this context involves taking full account of the numerous influences already thought to play a part. In the first instance, this involves consideration of age. Growing old is not only a biological process, it is a social construction brought about by the ageist policies and negative attitudes towards older people that permeates Western society (Townsend, 1981; Phillipson, 1982; Vincent, 1995, 2000; Tinker, 1997a; Gibson, 1998). For example, all these authors suggest that the statutory retirement age for men and women strongly influences public perceptions of when people become 'old'. Traditionally, the period of 'old age' has been undervalued due its association with of a lack of economic power and peoples' increased dependence on the state, particularly for health and social care services Falkingham, (1987). As Fennel, Phillipson and Evers (1988: 54) explain, there was a time when anybody over the age of sixty-five years was likely to be dealt with, particularly by health and social care services, in a very negative way:

‘Older people may find themselves treated and processed as commodities. Welfare services are criticised for stigmatising older people and compounding their problems through the imposition of age related policies’

This quote serves to show how fundamentally chronological age can affect an individual's status and health chances. Recent Government policy marks a sea change in political attitudes towards older people as it acknowledges and aims to dismantle ageist practices in the care sector (DoH, 2001B). Even so, the lack of citizenship status afforded to older people, and in particular, to the minority of older people with long term health and social care needs, continues to be seen as a major barrier to the social inclusion of this group of

people (Higgs, 1999; Thompson and Thompson, 2001; Blackman, Brody and Convery, 2001).

One of the areas identified by Government as a priority in terms of improving health chances for older people is mental health (DoH, 1997; DoH, 2001b). The least treatable and arguably most disabling mental health condition to affect an older person is dementia. Dementia is a term used to describe a set of illnesses (such as Alzheimer's Disease - AD) which are characterised by a gradual and progressive inability to function cognitively (Alzheimer's Society, 1999a). The criteria most commonly used in the UK for diagnosing a dementia like AD include memory decline and thinking impairment (McKeith and Fairbairn, 2001:8/9) - abilities on which social inclusion depends. Hence, dementia is the second major influence for this study to consider as strongly shaping meanings of exclusion and inclusion.

It is estimated that some form of dementia affects approximately 700,000 people in the UK population; as age is the greatest risk factor the majority of those affected are people aged sixty-five years and over (approximately 680, 000) (Alzheimer's Disease International, 1999a). The prevalence of the condition is also slightly higher amongst women (McKeith and Fairbairn, 2001). As the illness progresses people affected are increasingly disabled by both the impairment and the world around them. For example, the physical design of internal and external spaces is thought to compound the disorientation that people affected face (Marshall, 1997; Blackman et al, 2003). Like growing old, becoming ill with this condition is not only a biological process it is a social construction *based on the practices* and beliefs of the medical profession and charitable bodies (Harding and Palfrey, 1997).

A third major influence thought to shape meanings of exclusion and inclusion is living in a care home. The negative effects of institution life are well theorised. Studies by Goffman (1968), Miller and Gwyne (1972) and Seligman (1975) all suggest that heavily routinised



and task orientated practices in an institution lead to high levels of dependency and loss of identity amongst care recipients. Older people with dementia have been the largest single group of older people receiving institutional care for many years (Woods, 1995). Numbers of older people with dementia living in some form of institution is estimated to be in the region of 300,000 people in the UK (Audit Commission, 2000). Of these, the vast majority will live in one of the 12, 763 care homes in England for people aged 65 years and over.<sup>1</sup>

The potential this form of housing has for shaping meanings of social exclusion is evidenced when one considers its former function. Historically, care homes have been places where older people with dementia were simply 'warehoused' and left to disengage from society (Kitwood, 1997). The modern policy ethos of 'community care' reinforces the negativity that surrounds institutional based care, as service planners and providers often see it as a 'last resort' for older adults with intensive support needs rather than as a positive, appropriate and beneficial living arrangement (Oldman and Quilgars, 1999). These negative perceptions of institutional life contribute to meanings of exclusionary by stigmatising and lowering the status of both this form of housing and the individuals who live (and work) in it.

Meanings of exclusion and inclusion are further shaped by the extent and nature of inequalities that exist in relation to this form of housing. For example, older people in care homes are more likely to be: affected by depression (Baldwin, et. al. 2002), undernourished (Alzheimer's Society, 2000b) and deprived of access to mainstream health care services such as a primary health care (Schneider et al, 2001) and dentistry (Paterson, 2000). As well as health inequalities, economic inequalities also exist in relation to care homes, as the majority of older adults are obliged to sell their own homes to live there and finance their care (Royal Commission on Long Term Care, 1999). This is in exchange for

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<sup>1</sup> This figure is based on Community Care Statistics: personal social services for adults, England (2001). It is the combined figure for care homes for 'older people' and for 'older mentally infirm people'.

no legal rights to accommodation or housing tenure (Wagner Development Group, 1993). Despite the range of inequalities that exist in relation to residential care homes they have not so far been considered in terms of a social exclusion phenomenon.

Long-standing concerns about the lack of access that older people in care homes have to mainstream society led to the recent introduction of National Minimum Standards (NMS). This guidance is designed to 'secure the welfare and social inclusion, of the people who live there (DoH, 2000: vii). Thus, modern care homes should not only be striving to meet the care needs of individuals but also ensuring their social rights as citizens are maintained. However, as many of these standards are not explicit enough to meet the inclusion needs of older adults with dementia, particularly those in the advanced stages of the illness, doubts remain as to whether these standards are sufficient to bring about social inclusion for this group of people as well (Alzheimer's Society, 2000a).

While recent decades have seen a wave of interest in improving conditions in care homes for older people, younger people with a physical disability have questioned why they should be in a care home at all; indeed, the asking of this question in the early 1980's by one young man with severe physical disabilities was what sparked the Disability Movement in this country (Campbell and Oliver, 1997). Much like feminism and the gay rights movement, the disability movement makes political the personal experience of discrimination and social inequality. Arguably, the movement has succeeded, as not only is discrimination on the grounds of disability now unlawful in certain circumstances, but also younger people with a physical and/or sensory disability are the second smallest client group living in care homes (Community Care Statistics, 2001). Part of the achievement of the disability movement is the creation of a social model of disability designed to divert attention away from 'impaired individuals' to barriers that exist in society (Tregaskis, 2002). A similar approach is slowly developing in the area of dementia studies (Kitwood, 1997; Downs, 2000). However, unlike this work the social model of disability is *only* concerned with the power that society has to exclude and stigmatise people with

impairment. Thus, a review of the theoretical principles underpinning the social model of disability would focus this study on influences shaping meanings of exclusion and inclusion.

### **1.3 Timeliness of the study**

This study is timely for three key reasons. In the first instance, the phenomenon of social exclusion is very much a matter of political concern. The Social Exclusion Unit (SEU), which was set up by the Labour Government in 1997 to investigate this phenomenon, has recently been asked to examine the factors influencing the social exclusion of people with mental health problems (SEU, 2003). The request follows a Scottish based survey of public attitudes to mental health and well being which found that exclusionary practices in relation to people with mental health problems still persist, particularly in the workplace. Because of the over emphasis on meanings of social exclusion to those of working age (Levitas, 1996) there remains a cavity of knowledge in relation to what it means to older people with mental health problems (MIND, 1999).

Second, the study is timely as Government increasingly focuses its attention on mental health services for older people (DoH, 1997, 2001b; 2003a). This attention is welcome as it could potentially reduce exclusionary processes currently brought about by a lack of funding (Burns, Denning and Baldwin, 2001) inequity in service provision across England and Wales (Audit Commission, 2000, 2002) and degrading and abusive care practices (Commission for Health Improvement, 2001; 2003). As the 'voice of the consumer' is increasingly recognised as needing to be heard (Cortrell and Schulz, 1993; Allen, 2002: 125), a small-scale study of meanings of exclusion and inclusion to consumers (with dementia) of residential care services is politically and culturally appropriate.

Third, the study comes at an opportune moment intellectually, as the idea of dementia as a disability is in the embryonic stages of development (Kitwood, 1997; Bond, 1999; Downs, 2000; Blackman, 2003). A systematic analysis of the relevance of the social model of disability to understanding this group of people is therefore extremely well timed if not long overdue. Throughout this thesis the primary concern is with understanding what social exclusion means to older people with dementia in care homes. Therefore, the contributions this study makes to the theoretical development of the social model of disability should be seen as a valued adjunct to that central endeavor.

#### **1.4 Locating the researcher**

The importance of locating one's own motives and position as a researcher is highlighted in the qualitative research literature. This body of methodological work suggests that rather than trying to pretend that the agenda of the researcher has no bearing on the research process, the 'writer's voice' should be heard along with that of the research subjects (Holliday, 2002). An increasingly accepted way for qualitative studies to make sure that the writer's voice is heard and to ensure that contact between the researcher and the researched is maintained is by using the first person pronoun. As Holliday (2002: 143) says, 'the use of the first person is a major device of separating the researcher's agenda from the other voices in the text, thus increasing transparency in the text'. Therefore, hereafter, the first person pronoun is used to make clear my agenda and experiences in relation to the social exclusion of older people with dementia in care homes.

As a mental health nurse with clinical experience of working with older people with dementia in long-term care settings my background clearly has bearing on this study. In the first instance, it perhaps explains why I undertook a study that is qualitative in design. Cutcliffe and Goward (2000) suggest that mental health nurses are naturally drawn to qualitative work, because it allows us to explore peoples' thoughts and feelings about the social world in which they live, in much the same way as we did as nurses. Another reason,

according to Allen (2001: 391) for nurses' attraction to this type of research is because the skills involved in managing yourself during nurse training are similar to those needed for ethnographic fieldwork. As she says, 'having moved around a succession of wards over the course of their training they are expert at negotiating access and carving out a role as a marginal member of a setting'. Both explanations have resonance with me, and indeed spending time in a care home and interviewing people with dementia and their families was probably the aspect of the study that I enjoyed most. However, I would add that my experiences of nursing older people with dementia hindered as well helped me in my role as a researcher. For example, at the start of the study I made a number of, what I see now were highly medicalised assumptions about how well a cognitively impaired person would be able to contribute.

My background also has bearing on this study as returning to nursing after studying cultural politics at postgraduate level, I found caring for someone with a mental health condition like dementia increasingly difficult. My discomfort was due partly, I suspect, to my heightened awareness of how much power health care professionals have in relation to older people with a mental illness. I can recall on at least two occasions, while staff nursing on a busy assessment unit for older people with mental health conditions, when I considered how relatively powerless patients were. One incident occurred one morning when I went to help a female patient on the ward to get up. An eighty-year old woman was in tears because she could not understand where her husband was, who I was, and why she should be waking up where she was. The magnitude of what she felt struck me as I too cried. Whilst I think my response was positive, as it was on that basis that I built a trusting relationship with the patient, it made me realise how sensitive I had become to the impact of mental ill health on an individual. The second incident was when the ward doctor filled in a form to justify why a patient should be detained under the Mental Health Act (1983). He completed the clinical details without speaking to or apparently assessing the patient at

all. An incident that made me realise how seemingly acceptable it is in clinical practice to not seek the opinion of someone affected by dementia.

These types of event made me seriously question what it was that most disempowered older people with dementia. Prior to studying sociology at degree level I had assumed that the disease process was the most disabling factor in peoples' lives. So, when a case studentship was advertised that involved looking into the social exclusion of older people with dementia, and thus allow me to investigate other possible influences including care practice, I knew I should apply. My experiences and knowledge as a mental health nurse clearly shaped my agenda as a researcher. So too did my academic background in social and political theory. According to Bauman and May (2001: 11) 'to think sociologically can render us more sensitive and tolerant of diversity'. This would certainly explain why I had become more emotional and questioning as a nurse. As I re-immersed myself in sociological theories prior to fieldwork for the case studentship this time, of course, the literature related very much to older people with dementia in residential care I remained highly attuned to the concept of oppression. A point one of my supervisors made during a supervision session in year two:

You have been out of practice now for 18 months, perhaps you have become sensitive to people's situations, all the reading you've been doing and the deep thinking. When you go in and are faced with a very familiar situation – a lady in a nursing home who is not very happy – it's bound to cause distress.

My supervisor was referring to a woman I had spoken to about taking part in the study. The woman's situation and my response to it were very similar to that of the 80-year-old female patient I met whilst staff nursing. However, on this occasion I was as powerless as someone with dementia, and so my interest in exclusionary factors was once again raised.

## 1.5 The research questions

The central objective of this study is to understand the meaning of social exclusion and inclusion to older adults with dementia in care homes. A number of specific questions were designed to direct and guide my understanding of these meanings. These are detailed in Box 1. A full explanation of the research questions is given in Chapter 4. At this point the questions are introduced to show how the different possible influences shaping social exclusion were broken down. The research questions are in part questions derived from my own nursing experiences (Swanson, 2001). That is to say, having worked in a number of different residential care homes nursing older people with dementia I already had a strong sense of what it was that people found disabling.

<b>Box 1 The research questions</b>	
<b>Major Research Question</b>	
1	What does social exclusion mean to older people with dementia in care homes?
<b>Subsidiary Research Questions</b>	
2	To what extent do economic, social and legal conditions shape meanings of social exclusion and inclusion?
3	To what extent does the organisational context of the care home shape meanings of social exclusion and inclusion?
4	To what extent do normal biological processes of ageing and ill health shape meanings of social exclusion and inclusion?

## 1.6 Orientation to structure of thesis

The thesis is organised into four main parts. The first part, of which this chapter forms a section, comprises of three chapters in total. Each chapter sets out a vital aspect of the background and rationale for the study. This chapter has introduced me, and the general focus and timeliness of the study. In the first half of the next chapter - Chapter 2 - the

social exclusion literature is explored and critiqued in considerably more detail. Close attention is paid in particular to the way that social exclusion has become defined and measured by Government and social scientists, a focus that highlights how open to interpretation the concept of social exclusion is. The second half of Chapter 2 reviews the gerontological literature particularly as it relates to ageing with a dementia in a residential care home. That discussion suggests that whilst this group of people is at some risk of becoming excluded from mainstream society, very little work has gone into finding out whether this is indeed the case, or, what that might mean at an individual level. The final chapter in Part One - Chapter 3 – evaluates what seems to be a compelling and comprehensive argument for why people with a disability are excluded from mainstream society– that is, the social model of disability. Key questions are raised in this discussion, most notably, why no researchers have yet applied the model to the situation of older people with dementia in residential care.

Part Two of this thesis describes how, where and with whom the study was conducted. Chapter 4 describes the methodological context for this study and also the qualitative methods that were used to collect and analyse data. This chapter also considers the ethical components to this study including gaining formal and informal consent and my training and supervision needs. Chapter 5 introduces participants and study sites. A number of different people and care homes volunteered to take part in this study and so this chapter contains the profile of each of the four sample groups and five study sites.

Part Three of this thesis responds to the research questions as set out in section 1.4. of this thesis. This part comprises of five chapters in all. The first chapter - Chapter 6 – considers the influence of economic and social conditions on meanings of social exclusion. The next two chapters explore the organisational influences shaping meanings of social exclusion. Chapter 7 deals with the broader context of care home life such as location and organisational values and ethos. Chapter 8 explores the impact of operational factors on



peoples' levels of participation, including care practices and mix of residents. In Chapter 9 the impact of poor health status is explored. Finally in this section, Chapter 10 examines the ways in which people in this study resisted exclusionary influences by seeking to maintain and develop a sense of identity.

The fourth and final part of this thesis comprises of two chapters. These are both concerned with the implications that this study has for social theory, policy, and practice. In Chapter 11 I reflect upon the usefulness of the social model of disability for understanding and meanings of social exclusion in the context of older people with dementia in care homes. In addition, this Chapter considers how this study might inform the mounting endeavor to include people with dementia in all aspects of social research. Finally, the thesis concludes by exploring in Chapter 12 the implications that findings from this thesis on theoretical and policy debates within relevant fields of study.

## **CHAPTER TWO**

### **Study Background: social exclusion, dementia and care homes.**

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#### **2.1 Introduction**

The overall aim of this chapter is to highlight where the gaps are in our understanding of social exclusion, and thereby provide the intellectual rationale for this study. The chapter is organised into two parts. The first part presents and explains what is known about social exclusion; this is where gaps in knowledge about what social exclusion means in specific contexts are revealed, and the need for more qualitative ways of evaluating it are highlighted and discussed. The second part of the chapter focuses on processes of exclusion and inclusion in specific relation to older people with dementia in care homes. The central objective of this section is to explore how much is known about the factors that shape processes of exclusion in this context, and how individuals in this situation are thought to encounter and control them. Lastly, the chapter draws on findings of this review and offers a working definition of social exclusion so that an empirical study of it in relation to older people with dementia in residential care can be undertaken.

#### **2.2 Introducing the phenomenon of social exclusion.**

The general consensus is that the actual phrase 'social exclusion' was first coined by French sociologists during the 1980's to describe the lack of social and economic cohesion in the country at that time (Bhalla and Lapeyre, 1997, Burchardt, Le Grand and Piachaud, 1999, Byrne, 1999; Percy-Smith, 2001,). These authors describe how quickly the term gained widespread currency throughout the European Union, including Britain, where it is has since become everyday parlance amongst both social scientists and Government agencies. Given the Europe-wide interest in this phenomenon, understandings of it tend to be culturally based and developed according to national and regional interests (Blackman, Brodhurst and Convery, 2001). In Britain, for example, considerable attention has so far been paid to the relationship between social exclusion and poverty (Burchardt, Le Grand

and Piachaud, 1999). There are however a number of key characteristics which underpin understandings of social exclusion.

One of the main characteristics of exclusion as a social phenomenon is that it is a process rather than end-state. It is unhelpful, says Byrne (1999: 121), to talk of people as 'excluded', instead, think of individual and communities as moving in and out of excluded spaces. Similarly, Hills, Le Grand and Piachaud (2002) consider one of the advantages of social exclusion as a theoretical concept is that it draws attention to dynamics and changes over time. This then avoids the idea of certain groups and communities being permanently cut off from society – like an underclass. The term is clearly intended to convey a process rather than to serve as an enduring marker. Another key characteristic of this phenomenon is that it is multi-dimensional. Virtually all social exclusion theorists write of the multi-faceted nature of this concept (Byrne, 1999; Percy-Smith, 2001, Hills, Le Grand and Piachaud, 2002). This is because the meaning of social exclusion goes beyond that of poverty by 'explicitly embracing the relational as well as distributional aspects of poverty' (Bhalla and Lapeyre, 1997: 413). Social exclusion is not, therefore, a product of any one thing, and feelings of isolation and not belonging are about more than economic hardship. Clearly there are factors other than lack of money influencing the process of exclusion: it is about being impoverished in every sense of the word.

In the subsections that follow, the different meanings and dimensions of social exclusion are reviewed so as to make clear the full extent and nature of this phenomenon. Discussion begins by setting out the policy context in which studies of social exclusion are undertaken. Then the different definitions of social exclusion are presented and explained followed by a discussion of the influential factors which are thought to bring it about. Finally, current indicators of social exclusion are discussed and analysed along with present strategies for inclusion.

### ***2.2.1 Setting the policy context***

This section examines the policy framework in which ideas about social exclusion are expanding and developing. Discussion highlights how the policy focus on the circumstances of younger people and the state of worklessness has the effect of marginalising those who for whatever reason are unable to work (Levitas, 1996) – such as older people with dementia living in residential care.

The phenomenon of social exclusion has only recently become an explicit focus of Government policy. Policy initiatives based on this concept started to develop in 1997 when the Labour Government set up the Social Exclusion Unit (SEU). To date most of the work undertaken by this Unit has been concerned with understanding meanings of exclusion in relation to young healthy people. The mental health related investigation mentioned in section 1.3 of this thesis denotes the first shift away from this focus. Reports by the SEU such as ‘Teenage Pregnancy’, ‘Truancy and Social Exclusion’, and ‘Young Runaways’ reflect not only the extent to which Government uses the term primarily in connection with young and healthy populations, but also how readily the term is linked to a particular situation or circumstance, like pregnancy or truancy. The link or ‘cause’ of social exclusion is therefore presupposed within the policy context.

The other area of policy in which social exclusion has had an impact is the neighbourhood renewal programme. This programme of work has identified a number of regions around the country, deemed to be deprived, and invested considerable amounts of money into them. The hope is that with more financial investment a locality can provide all its citizens with the same level of access to opportunity (Blunkett, 2000). The neighboured renewal programme, like the work of the SEU, is clearly quite narrow in its focus on what social exclusion means and whom it is likely to affect: social exclusion is about being out of work, and as such affects the (potential) workforce (Levitas, 1996). The exemption of older people, and of people living in institutions from this policy context does raise immediate questions about Government’s understanding and application of the term ‘social exclusion’.

### **2.2.2 Definitions**

While there is broad agreement about the basic origins of the term, what is less certain is what social exclusion precisely means in any given situation, and at what point it becomes meaningful. In British politics, for example, the term 'social exclusion' has become an accepted way of describing a range of social problems. The SEU defines social exclusion as:

‘a shorthand label for what can happen when individuals or areas suffer from a combination of problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health and family breakdown’ (SEU, 1998).

In other words, the term provides Government with a single and arguably more appealing label than poverty, to provide a focus for dealing with society’s many intractable problems. Thus, as Byrne (1999) remarks this particular definition of the concept probably says more about government’s general role as ‘crisis resolvers’ than it does about social exclusion, as talking generally about ‘a combination of problems’ sheds little light on what social exclusion actually means or at what level of ‘suffering’ it becomes salient. That said, the fact that government has accepted and defined the term suggests that it has the potential to politicise a situation (such as ‘bad health’ and ‘family breakdown’) that might otherwise be seen as a personal rather than societal problem.

Other definitions of social exclusion are equally broad and open to interpretation. The Economic and Social Research Council’s social exclusion thematic priority (under which this study was funded) is stated as ‘understanding the processes by which individuals and their communities become polarised, socially differentiated and unequal’ (quoted in Burchardt, Le Grand and Piachaud, 1999: 243). Thus, the term ‘social exclusion’ is given meaning at an individual and local or community level and societal divisions and inequities are seen as key definitional aspects. Nevertheless, this description of social exclusion has little meaning unless and until it is deconstructed and interrogated to a greater extent. This is also the case with a sociology dictionary definition of the term:

‘social exclusion is a process by which individuals or families experience deprivation, either of resources (such as income) or of social links to the wider community or society’ (Marshall, 1998).

Again, this definition of the term manages to convey what social exclusion is broadly about, but leaves the meaning of key definitional aspects, namely ‘deprivation’ and ‘social links’, open to further interpretation and explanation. There remains a need for studies to seek to explain the definitional aspects of social exclusion.

Attempts to explain the meaning behind social exclusion phrases like ‘deprivation’ and ‘social links’ are sometimes based on the notion of participation. For example, Room (1995) sees social exclusion as a process of becoming ‘detached from the organisations and communities of which the society is composed and from the rights and obligations that they embody’. In this sense, social exclusion becomes less about a lack of resources (such as income and housing) and more about a lack of rights to participate. Similarly, Burchardt, Le Grand and Piachaud (1999: 230) operationalise the concept of social exclusion based on the notion of participation, and as such define social exclusion using the following criteria: ‘an individual is socially excluded if (a) he or she is geographically resident in a society and (b) he or she does not participate in the normal activities of citizens in that society’. The authors suggest that in Britain the five activities, considered normal for individuals to be involved in, or at least have access to on a regular basis, are (1) consumption (2) saving (3) production (4) political and (5) social engagement.<sup>2</sup> However, whilst a criteria of non-participation provides a clear and simple model for defining social exclusion, what is not clear from this definition is at what level of non-participation does the term ‘social exclusion’ become salient; when a single individual is unable to participate, or when an entire social group ‘misses out’ on being able to do these mainstream activities? Uncertainty also remains as to who is responsible for non-participation: globalisation, the nation state and its organisations, or excluded individuals themselves (Hills, Le Grand and Piachaud, 2002). Clearly, there is a need for studies to seek to identify and understand the interactions between influences at all levels – societal, organisational, and individual.

Writing from a disability perspective, Ravaud & Stiker (2001) consider questions of responsibility to be the key to defining the meaning of social exclusion and inclusion. These authors liken the concept of social exclusion to the classic Durkheimian notion of 'anomie'; anomie essentially signals breakdown and disintegration of either a social structure or an individual (Marshall, 1998). Durkheim's explanation of the concept, particularly in relation to how it manifests itself at a psychological level; disrupting peoples sense of belonging and social identity (Campbell, 1981) is clearly pertinent to a discussion about the meaning of social exclusion (Ravaud & Stiker, 2001), not least because the theory highlights the importance of being involved in everyday life from an individual perspective. As Twine (1998: 105) remarks, 'inclusion in a society is essential to our identity and development'. In light of existing literature, social exclusion is clearly a contested term; there are still questions about what it means, particularly for an individual affected by the process.

### ***2.2.3 Influential factors***

The main influences shaping exclusion processes are economic, social, and political in nature and form (Bhalla and Lapeyre, 1997, Byrne, 1999, Percy-Smith, 2001). All these researchers believe that exclusion by one of these influences is likely to bring about exclusion by another. Certainly for people with mental health problems, social exclusion is considered a 'compound process' in that isolation in one area of life often leads to isolation in another (MIND, 1999). So, when talking about the influential factors in social exclusion it may not always be possible or appropriate to single out any one influence or dimension. Nevertheless, for the purposes of this review so as to distinguish between the different influential factors, the three categories of economic, social, and political influences are used as themes to organise discussion.

Economic influences in the social exclusion of people are about lack of income and access to goods and services (Bhalla and Lapeyre, 1997). Most if not all studies of social exclusion focus upon this aspect of social exclusion (see Room, 1995; Walker and Walker,

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<sup>2</sup> These activities are explained in more detail in 2.2.4

1997; Scharf et al. 2000). The high concentration of interest on this particular dimension of social exclusion is partly explained by the financial imperative to help people get back into work and thereby reduce public spending. It is also explained by the long-standing belief in low income as *the* key indicator of social exclusion. Consequently, much is known about economic influences in the social exclusion of individuals and communities but less about cultural or personal influences such as health. While not wishing to downgrade the difficulties associated with a low income, sometimes it might be as, if not more instructive to take the issue of poverty to another level. For example, within the field of cultural studies, when questions about what human beings should have are posed, 'what seems to be at stake is not the possession of material property as such, but access to opportunities to give shape and form to one's own life' (Shotter, 2001: 192). Future studies of social exclusion might therefore be as well as to adopt a broad view of poverty, and to focus upon what people want to *be* as well as what they have.

Social influences stem from a lack of access to people, relationships and key services such as health and education (Bhalla and Lapeyre, 1997). Not being acknowledged or spoken to when entering a populated room could be construed as social exclusion in this form at a very basic level. This is because 'our social selves are only able to assume significance if they are recognised, responded to and confirmed by others (Hill, 1995: 67). This understanding of social inclusion brings with it a sense of human dignity which if intact increases the scope for social participation (Bhalla and Lapeyre, 1997). For older people with dementia living in residential care, this can be affected by a number of different factors including age discrimination and the stigma associated with mental illness (Sayce, 2000). Because government makes global decisions in the management of the national economy (such as when to issue a state pension) any individual (who receives a state pension) is perceived to be not only 'old' but also dependent (Townsend, 1981). In this sense, opportunities to participate in everyday life are limited not (necessarily) by how a person feels about themselves but by 'the outward labelling' that is mediated through wider social processes and policy structures (Byrne, 1999). Social attitudes undoubtedly form a vital element in the lived experience of social exclusion (Burden and Hamm, 2001).



Political influences in the social exclusion process relate to a lack of political expression and to the denial of other human rights (Bhalla and Lapeyre, 1997). This influence is perhaps most strong and apparent in the case of socially excluded groups (Burden and Hamm, 2001). For example, Chapter 3 of this thesis is about the lack of political rights and expression afforded to people with a disability. This is a group who historically have been seen as pitiful, abnormal and devoid of power (Charlton, 1998). Consequently, the human rights of people with a disability have often been denied or restricted by the stigma associated with disability and impairment (Coleman, 1997). One of the few studies of social exclusion in relation to older people makes a similar point about the political influences on exclusion processes:

‘Social exclusion is actively produced through the norms and values that govern both civil society and public services - by denying rights to certain groups, by making unfair or inconsistent judgements, by allocating resources indiscriminately or on the basis of patronage or corruption, and by stigmatising sections of society perceived to be less productive or deviant in their behaviour and beliefs’ (Blackman, Brodhurst and Convery, 2001: 235).

In this sense, opportunities to participate in everyday life are limited not (necessarily) by how a person feels about himself or herself but by ‘the outward labelling’ that is mediated through wider social processes and policy structures (Byrne, 1999). Reviewing conceptual and empirical work in the area of social exclusion there has been little, if any, cross-fertilisation of ideas regarding the agency, or power that individuals have in relation to exclusionary processes. That is to say, the tendency has so far been to define the concept according to broad macro structures rather than individual experiences. This is partly explained by the methodological approach usually taken to investigating it; and it is to this issue discussion now turns.

#### **2.2.4 *Researching social exclusion***

Social scientists have always been interested in ‘measuring’ social phenomena – that is, surveying the extent to which something (a social process) happens at a situational, local, national or international level. Generally speaking, this is achieved in empirical research by using quantitative techniques (such as postal surveys), qualitative methods (such as in-

depth interviews) or a combination of both (Robson, 1998). Given the Europe-wide interest in social exclusion as both a theoretical concept and social problem, studies of social exclusion have tended to favour the former methodology and as such researchers know an increasing amount about the quantifiable global indicators of social exclusion (such as income, unemployment, educational attainment) and also the scale of public opinion in relation to what constitutes as poverty (Golding, 1995), but very little about the qualitative and situational dimensions of the process, including what individuals mean by social exclusion and how they perceive of their particular circumstances (Mouleart, 1995: 176).

The consequences of using this methodological approach to gauging levels of social exclusion have been noted. Researchers are increasingly aware of the dangers involved in making assumptions about (or ignoring completely) peoples' experiences of a situation. For example, Reay & Lucey (2000) investigated the meaning of social exclusion to children living on a London borough council estate that the SEU had categorised as a 'socially excluded' area. What these researchers found was that the children who they spoke to had relationships with the places in which they lived, which were characterised by 'ambivalence and conflicting feelings of longing, belonging and abhorrence' (Reay & Lucey, 2000: 411). Whereas other studies automatically equate poor housing with social exclusion (Kristensen, 1995) by using a qualitative approach Reay and Lucy (2000) discovered this is far too simple an equation to make; contrary to what an outside observer might think, council estate living can be both a negative and positive experience. The same discovery might be made with a social exclusion study of residential care, as this too is often seen as a 'last resort' for older people in need of long term care, (Oldman and Quilgars, 1999) and so the positive aspects of communal living in later life are seldom explored (Nolan et al, 1996).

Studies of social exclusion are usually based on the assumption that exclusion is necessarily a negative process. However, this does not always have to be the case. For example, the former nurse and journalist Claire Rayner (2000: 47) describes 'how being excluded from one group meant that (she was) automatically included in others'. While this was a reflection on her experiences as a Jewish woman (rather than of being older and

unwell) it does highlight how marginalisation from one part of society might lead to more solid identities forming with another. Might a similar process occur for an older person with dementia moving into a care home? The investigative tools that a social exclusion study adopts obviously need to be sufficiently flexible to measure the fluidity that occurs between exclusion and inclusion, and allow for the possibility that exclusion might mean different things to different people. As Bhalla and Lapeyre (1997: 431) say there is a growing need to develop ‘methodologies and indicators’ for investigating the *experience* of social exclusion, as well as its material dimensions.

Other studies of social exclusion which have favoured a qualitative approach have found that social exclusion is experienced as either discrimination or social isolation or both. This was the finding of O’Connor and Lewis (1999), for example, when they assessed the extent and nature of social exclusion across Scotland. A large-scale inquiry into social exclusion by MIND (1999) also found that people with mental health problems were susceptible to exclusionary practices such as discrimination at home, at work, and amongst friends and families, and experienced varying degrees of social isolation as a result. These studies are revisited in section 2.3. of this thesis. The point to make here is that there is a need for more studies of social exclusion which seek to explain what exclusion and inclusion mean to individuals and communities.

### ***2.2.5 Strategies for inclusion***

Current strategies designed to tackle social exclusion tend to be based on the assumption that work is the main – if not the only - route to social inclusion (Levitas, 1997). As already stated at the beginning of this chapter an overemphasis on work-based solutions to social exclusion runs the risk of marginalising those who for whatever reason are unable to work. MIND – a leading mental health charity – has expressed concern about Government’s persistent emphasis on training, education and jobs as means of dealing with social exclusion. An inclusive society, they say, is one which maximises opportunity for each individual (MIND, 1999). An alternative framework for inclusion, favoured by those who write in the field of mental health, is that of citizenship (Sayce, 2000; Barnes and Bowl, 2001).

Citizenship refers to the rights and duties of a member of a nation state (Marshall ed. 1998). The concept is a recurrent theme in the social exclusion literature, and as such requires critical review. As Lister (1997: 15) explains most of the accounts of citizenship in this area of literature take as their frame of reference the three elements expounded by Marshall (1950). These are civil, political and social rights:

The civil element is composed of the rights necessary for individual freedom – liberty of the person, freedom of speech, thought and faith, the right to own property and conclude valid contracts, and the right to justice. The last is of a different order the others, because it is the right to defend and assert all one's rights on terms of equality with others and by due process of law...by the political element I mean the right to participate in the exercise of political power, as a member of a body invested with political authority or as an elector of the members of such a body...by the social element I mean the whole range from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilised being according to the standards prevailing in society (Marshall, 1950: 10-11, quoted in Lister, 1997: 16).

The exercise of these rights is a prerequisite for social inclusion. The concept of citizenship is a potentially useful one for promoting the inclusion of people with dementia, as it improves their status and it makes explicit the meaning of participation. However, due to the dominance of the psychological notion of personhood in dementia studies (Brooker, 2003) the model of citizenship is rarely applied to this group of people<sup>3</sup>. Even in the most recent edited volumes on dementia, the concept of citizenship is hardly mentioned: dementia denotes care needs, not citizenship rights (Adams and Clarke, 1999; Cantley, 2001, ed. 2001b; Adams and Manthorpe, ed. 2003). That is not to say that the rights of people with dementia are not considered in the literature, as they are (Kings Fund Centre, 1986; Higgs, 2001) but that the lack of individual rights is usually perceived of as a sign of poor services or practice rather than of wider processes of exclusion (Opie, 1992; Parker and Penhale; 1998; Cox, et al. 1998).

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<sup>3</sup> The notion of personhood is discussed in section 2.4.3 of this thesis.

## **2.3 Introducing the phenomenon of dementia**

The phenomenon of dementia has generated an extensive volume and diverse range of research. In this section, studies that shed light on how and why an older person with dementia might experience exclusionary process are reviewed. This literature and my discussion of it is organised into four subsections, these are (1) the medicalisation of dementia (2) the policy context (3) living with dementia: understanding the experience, and (4) modern developments in dementia care. While no study has so far been explicitly concerned with processes of exclusion, by reviewing these areas of literature the variety of and gaps in knowledge that do exist are identified.

### ***2.3.1 The medicalisation of dementia***

Scientific medicine has so far dominated understandings of dementia (Downs, 2000). Therefore, much is known about how the illness impacts the brain, and in particular, about the physiological and behavioral changes that take place. The features a clinician would expect to see in a person to make a diagnosis of dementia are defined as thus:

(I)impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. Consciousness is not clouded. The cognitive impairments are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain (WHO, 1993, cited in Cooper, 1997).

From a biomedical perspective then, dementia is defined in terms of a syndrome due to disease of the brain, usually of a chronic or progressive nature. The diagnostic process usually begins when forgetfulness and language problems become so noticeable and troublesome for a person that that person seeks medical advice from their General Practitioner (Keady, 1996; Audit Commission, 2002). At this stage a series of tests, including a CT scan and Mini Mental State Examination (MMSE) are usually carried out on the basis of which a diagnosis of dementia may be made (Cheston and Bender, 1999). As a person's mental and physical abilities progressively deteriorate their life might then be described in terms of a 'social death' in that the person has to all appearances died and

gone (Sweeting & Gilhooly, 1997). Arguably, a clear indicator of the degree of exclusion that dementia can bring about. Since the first person was diagnosed with a dementia in 1909 the incidence of dementia has risen steadily each year (Cheston and Bender, 1999). Consequently, the scientific community constantly strives to find a cure for dementia or at least find out more about other risk factors such as hypertension and diabetes (Parsons, 2003).

Concerns about the medicalisation of dementia, whereby behaviour is defined as a 'medical problem' and the medical profession is therefore seen as the best group of people to remedy it, are raised in the literature (Bond, 1992: 399). This area of debate stretches into wider Foucauldian concerns about the power that biomedicine exerts in society generally (Fox, 1993; Lupton, 1997) and as such is highly influential in understanding how the medicalisation of dementia shapes meanings of exclusion. According to Harding and Palfrey (1997: 81) the main reason for the steady rise in dementia is not because of an ageing population (which, because age is a risk factor for dementia, is how the rising incidence of dementia is usually explained) but because of improved diagnostic powers and resources of the scientific medicine. These authors describe how diagnostic practices and technologies have meant that mental states (such as confusion) which were once seen as a 'normal' part of the aging process, have now become symptomatic of a disease with a name and specific pathology.

The suggestion that the medical profession is partly responsible for the high incidence of dementia reflects wider concerns in the literature about the basis on which a dementia diagnosis is made. Kitwood (1997) Cheston and Bender (1999) and Harding and Palfrey (1999) all cast doubt upon the link between neuropathology and dementia that biomedicine frequently makes. As well as suggestions that this is because characteristics of dementia were once seen as a 'normal' part of the ageing process (Gubrium, 1997). Another plausible explanation is that people generally (want to) believe what 'medical experts' tell them, possibly because clinical explanations emanate from well organised and produced forms of knowledge, and thus are comprehensive enough to be convincing (Foucault,

1980). From a functionalist perspective, a diagnosis of dementia also benefits wider society, as Innes (1997) says:

‘By categorising individuals as demented, society can re-impose order onto the situation that is difficult to understand and, in the process, label the person with dementia as different and therefore potentially deviant in some way’.

The labels that the medical profession use to classify and describe people can have a profound effect on the status of someone with a disability. A diagnosis of dementia, for example, is not dissimilar to the experiences of someone diagnosed as having a learning difficulty in that whilst it can open doors to specialist services and treatment provision, both classifications are over-arching diagnoses which can shape identities and exclude people from mainstream opportunities and services (Gillman, Heyman and Swain, 2000).

Reviewing the literature, there is a vast range of ordinary services and activities that people with dementia are excluded from, possibly because others see the medical diagnosis first, rather than the person (Kitwood and Bredin, 1992). For example, in terms of health and social care services, people with dementia are often excluded: from any discussions about their diagnosis or care plan (see Keady, 1996); by the speed and or detail of assessment processes (Woods, 1995; Keady and Bender, 1998) and from accessing intermediate care services (Nuffield Institute for Health, 2002) and psychological therapies (Burns, Denning and Baldwin, 2001). As the illness progresses, a person with dementia is at even greater risk of exclusion from services, for providers are often urged to ‘look after the carer’ as the person (with dementia) has to all appearances died and gone (Campbell, et al. 1996). Traditionally, people with dementia have also been excluded from research (Wilkinson, 2002). Even erudite studies of dementia care have not always sought the opinions of people with dementia, for example, Goldsmith (1996) largely speculates on the experiences of people with dementia (rather than seeking their opinion about). The medicalisation of dementia means that peoples’ experiences of this condition are colonised to the extent that people with dementia are *all* regarded as ‘sufferers’ who lack insight into their illness. The review of literature in section 2.2.3 of this thesis, and analysis of data in Chapter 9 shows how this is not the case, as the degree of impairment varies and fluctuates

between and within people (Foley, 1992). Thompson and Thompson (2001: 63) argue that unless the medicalisation of older people generally is challenged, this group of people will continue to be conceptualised as recipients of care, rather than as citizens.

### ***2.3.1 Setting the policy context***

In this section the policy framework in which ideas about dementia care practice in care homes are expanding and developing is briefly explored. It is argued in this discussion that because policy makers seem unclear as to whether dementia is a health or social issue (Cantley, 2001a) the rights of people with dementia are at particular risk of being undermined. Box 2 chronicles policy and key events in the past thirty years that have had an impact on institutionalised-based services for older people. The overriding concern for policy makers during this period has been to improve conditions within all aspects of service provision including care homes. One way in which policy has sought to achieve this is by drawing attention to the planning and commissioning arm of mental health care services. Documents such as The Rising Tide report and the Forget Me Not report. recommend that primary care and specialist services work more closely together and ensure that resources and training initiatives are in place to meet the multiple needs of older people with mental health problems. National Service Frameworks have recently been introduced to clarify exactly what the public sector needs to do and by when in this respect, thereby reducing regional variations in the quality and type of service provision (Cantley, 2001a). While such guidance is clearly important, the needs, and rights of an older person with dementia in a care home might be easily relegated, as service providers strive to reach wider Government targets for mental health services for older people.



**Box 2**

A chronology of policy and key events.

1983	Health Advisory Service - <i>The Rising Tide report: developing services for mental illness in old age.</i>
1984	Centre for Policy on Ageing - <i>Home Life: a code of good practice.</i>
1988	The Wagner Review. <i>Residential care: a positive choice;</i> First dementia services development centre established, in Stirling.
1989	Department of Health - <i>Homes are for Living In.</i>
1990	National Health Service and Community Care Act 1990.
1993	Department of Health – <i>Inspecting for quality: standards for the residential care of elderly people with mental disorders.</i>
1994	The Residential Care Forum formed.
1995	Disability Discriminations Act.
1996	Residential Forum - <i>Create a Home From Home: a guide to good standards</i>
1997	Department of Health – <i>Better Services for Vulnerable People</i>
1999	Sutherland, S - <i>The Royal Commission on Long Term Care. With respect to old age: long term care – rights and responsibilities.</i>
2000	Care Standards Act; Department of Health - <i>National Service Framework for Mental Health;</i> Department of Health - <i>Better care, higher standards: a charter for long-term care;</i> Audit Commission - <i>Forget me not report: mental health services for older people.</i>
2001	Department of Health - <i>National Service Framework for Older People.</i> Department of Education, Trade and Regeneration – <i>Supporting People: Policy into practice</i>
2002	Department of Health - <i>National Minimum Standards for care homes for older people.</i>

There is no 'dementia care policy' as such and so, because dementia is an age-related condition, people affected (regardless of age) are included in older people (rather than mental health) policies (Cantley, 2001b). The problem with this, argues Keady (1996), is that a person with dementia misses out on wider mental health initiatives such as the Mental Health Task Force, which is designed to help younger adults with enduring mental health problems to live with support in the community. A further problem when the particular circumstances of people with dementia are not properly considered is that policy directives aimed at involving service users more in the planning and evaluation of care services run the risk of marginalising the opinions of older people with dementia because appropriate tools are not used (Redfern, 1997). These issues are partly addressed in more recent Government initiatives.

A second means by which poor condition within care homes has been addressed is with the development of standards. To date much of the policy aimed at raising standards in care homes has been based on the circumstances of older people generally. This means that much is known about what older people in this situation need and have a right to expect such as independence, choice, to live in dignity and privacy and to have basic human rights safeguarded (DoH, 1989; DoH, 2001b). It also means though, that assumptions are made about what is important to someone with dementia, as traditionally this group of people have been a 'silent and excluded voice' from the service development agenda (Wilkinson, 2001). It might be, for example, that a sense of belonging and security are more important to a person with dementia than choice and independence (Martin and Younger, 2000). Clearly, policy makers need to find out what works for older people with dementia in care homes, as distinct from what works from the wider population of older people (Netten et al. 2001).

### ***2.3.2 Living with dementia: understanding the experience***

Arguably the best way of understanding the phenomenon of dementia is by reviewing what those who are personally affected say about it.

There is a growing body of literature that seeks to gain insight into the experience of dementia. As Reid, Ryan and Enderby (2001: 378) point out, the rise in (semi) autobiographical accounts of dementia, serve to show how the 'search for authenticity in the experience of dementia is well and truly on'. This work is helpful as it provides considerable insight into the internal world of an individual with dementia. However, as more and more attention is paid to subjective experiences of dementia a cavity of knowledge has become apparent as to what other influences shape the lives of those affected (such as gender and social class). Research by Bender and Cheston (1997), Cheston and Bender (1999) and Mills (1997) typify the trend in dementia studies to reflect on the psychological implications of living with dementia. Such work is underpinned by dominant theories of dementia, which also psychologise the individual (Kitwood and Bredin; 1992; Kitwood, 1993). It is suggested that dementia studies would benefit from a more sociological rather than psychological investigation (Downs, 2000).

Closer analysis of work by someone who researches care home settings reveals how an over reliance on psychological models creates a gap in knowledge about wider exclusionary processes. John Killick is a poet who interviews people with dementia in a range of care settings. While his style of research and dissemination is unconventional his work makes accessible peoples' experiences of dementia (Killick 1998). For example, this is how he conveys the words of one woman whom he interviewed living in a nursing home, as a poem;

'It's really scary when you're an old woman.  
I'm bereft. I hate being stranded like this,  
I want to down in the middle of town.  
But I have no money to speak of, and  
I don't know how to get away from here.  
I can't open it! The door won't open.

(Killick and Allen, 2001: 272).

By using poetic conventions the experience of care home life for this woman is powerfully portrayed. The problem I have with this work is not how peoples' experiences are disseminated but how they are contextualised. The author places this poem in the context

of loss and bereavement and so delimits the understanding of experience. If it were analysed sociologically other forms of exclusion might be identified including lack of status as an 'old woman', income, transport possibly (perhaps this was what meant by 'don't know how to get away from here') and rights as a citizen. The tendency to understand dementia using psychological constructs has led to a gap in knowledge about how wider social processes and structures impact on peoples' opportunities.

This gap in understanding is partly filled by other areas of the dementia studies literature which analyse peoples' experience of dementia using the concept of quality of life<sup>4</sup>. Consultation with users of older people services is high on the political agenda (Little, 2002; DoH, 2001b). Consequently, subjective accounts of dementia are explored to find out people feel about the quality of services they receive (Barnett, 2000). This area of the literature is useful as it identifies factors constituting a quality of life for people who are cognitively impaired. For example, Bamford and Bruce (2000) suggest that what is important to people with dementia is access to meaningful activity and a sense of social integration. These authors also identified having a purpose in life – 'somewhere to go and something to do' – as important to people in their study who were regular users of a day care centre (Bamford and Bruce, 2000:555). This has resonance with studies of care homes in which 'not going out enough' has been a recurrent and constant theme (Townsend, 1962, Meacher, 1972, Willcocks, Peace & Kellaher, 1987). Similarly, Logsdon (2002) uses the quality of life framework and suggests that what is important to a person with dementia is being able to do and have things which allows them to make the most of every day, such as money, physical health and friends. This information provides much needed detail as to the level and type of mainstream activity that an individual with dementia might wish to engage in. However, the quality of life literature sheds little light on *why* opportunities are not available to people.

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<sup>4</sup> The concept of quality of life is an elusive concept, well used in philosophical, medical and disability debates; therefore, it is beyond the scope of this thesis to review this concept in detail, other than to explain how it differs from the concept directing this study. A key difference between the concept of 'social exclusion' and the term 'quality of life' is that the notion of social exclusion is essentially a binary or relational one – that is, integral in the notion of exclusion is the notion of inclusion. In contrast, the term 'quality of life' is self contained, intrinsically whole. Thus, a social exclusion study is necessarily concerned

According to Bond (2000) the concept of quality of life has been so well used, particularly within the politically driven field of health and social care, that is no longer helpful for understanding older peoples' experiences. This author suggests that concepts like 'social inclusion' and 'equity' have far more utility in uncovering the factors that impinge on peoples' lives. Reviewing phenomenological studies of dementia suggest that this is the case. For example, Lyman (1998: 53) found in her study of people with dementia using a day care centre that what individuals feared was not the effects of impairment but 'being treated as 'old', with disrespect and invisibility' – in other words, processes of exclusion. Similarly, Proctor (2001) interviewed four older women with dementia about their experiences of services and analysis of data from feminist and disability perspectives uncovered the sense of powerlessness that people felt, particularly in their relationships with health care professionals.

It is usually assumed that it was not until the 1990's that subjective accounts of dementia were considered a valuable and valid source of information to collect (Cottrell and Schulz, 1993). However, this view overlooks the groundbreaking work of Meacher (1972) who included in his study qualitative interviews with people with dementia. This study also demonstrates the utility of an inclusion framework for understanding the experiences of people with dementia. This research was ahead of its time in that it identified a number of processes that today would be described as exclusionary. For example, Meacher (1972: 298) describes how some participants characterised their experience of care home life in terms of a 'subjective isolation in the midst of company'; here is one example he gives of an eighty-seven year old woman expressing such feelings:

'I'm a stranger here. I've never felt at home here. They've never trusted me here. They say a "silent tongue shows a wise head". You have to be very careful. It's not easy to make friends when you are old. I'm penned in. No *real* company. Not (people) with the same taste. I feel like a lone wolf' (op.cit).

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with how and why people miss out on things, whereas quality of life literature aims to find out what makes for a 'good life'.

Obviously the author did not analyse this narrative using the concept of social exclusion, however, if he had, he might have interpreted it as a clear example of how exclusionary processes relating to tenure, social divisions based on age, locality and lack of social support are experienced. Moreover, although this woman was described as ‘mildly confused’ that did not seem to be that aspect of her life that she found most troubling. Indeed, more recent studies suggest that dementia becomes another part of who a person is rather than their primary identity (Gillies, 2000). Clearly there is a need to delve deeper into the experiences of people with dementia; however, given how much is known about the psychological aspects of dementia perhaps now is the time to explore dementia from a sociological and political perspective (Bond, 1999; Downs, 2000).

### ***2.3.3 Citizenship and people with dementia: an overview***

This section reviews the large body of work that acknowledges people with dementia as persons (Foley, 1992; Gubrium, 1997; Kitwood, 1997; Gillies, 1997, 2000), and the growing literature that recognises people with dementia as service users (Barnett, 2000; Bamford and Bruce, 2001). In reviewing this burgeoning body of work it becomes apparent that little investigation has gone into this group of peoples’ inclusion as citizens.

The Kings Fund Centre (1986) was arguably the first to make explicit the status of people with dementia as citizens (Clarke and Keady, 2002). Since that time modern approaches to dementia care have largely been informed by the seminal work of Tom Kitwood and a small group of like-minded researchers (Kitwood, 1990, 1993, 1997; Kitwood and Bredin, 1992a, 1992b; Kitwood & Benson 1995; Goldsmith, 1996; Miesen, 1999; Killick and Allan, 2001; Brooker, 2003). The work of these authors combines to make a significant contribution to understanding meanings of exclusion in the context of people with dementia in care settings. However, as this section will now show, little is still known about the wider position of people with dementia.

One of the most significant contributions this area of work has made to dementia care and understandings of exclusion and inclusion is the notion of personhood. Personhood is defined as ‘a standing or status that is bestowed upon one being by others in the context of

a relationship and social being' (Kitwood, 1997: 8). It is the psychological equivalent of social identity. As Brooker (2003) explains the notion of personhood is adopted from the field of counselling and introduced into dementia discourse to offset the dominant influences of biomedicine, which can depersonalise and alienate a person with dementia. It is suggested that the discovery of the person with dementia and the focus on personhood is one of the most recent significant developments in the field of dementia care (Woods, 2001). This is because the individual is considered central and not the disease.

The strength of the notion of personhood is that it recognises different influences in the life of someone with dementia. Maciejewski (2001: 40) summarises what these are, a person's personality and resources for action, their biography, physical health, the neurological impairment and social psychology. In attending to all these influences it is assumed that the personhood of a person with dementia is maintained. However, even if this was the case, and the personhood of an individual with dementia was maintained through good practice and social relations, would that necessarily mean social inclusion to that individual? Citizenship theory argues not as social inclusion is ultimately defined by an individual's status as a citizen rather than a person. These more political dilemmas have only just begun to surface in dementia studies (Higgs, 2001).

As far as government is concerned the strengths of the personcentred model outweigh any weakness, which is why modern approaches to health and social care delivery are driven by this notion of personhood and of personcentred care (DoH, 2001b). Residential services for older people (with dementia) are expected to deliver care in a person-centered way (DoH, 2000). This involves training and supporting staff to interact with service users and provide care in a way that does not damage the personhood of an individual. Practices considered exclusionary to a person with dementia include banishment (removing a person from the human milieu), outpacing (going at a faster pace than a person with dementia) and disempowerment (doing things for a person even though they are able to do it themselves). These types of care practice are described as part of a 'malignant social psychology'; a phrase coined by Kitwood (1990) to describe the different social factors influencing the ill being of a person with dementia. While this framework informs understanding of how

important it is for organisations to attend to the process of care delivery, it is criticised for taking an overly individualistic approach to dementia care (Nolan, et. al. 2002). These authors argue for an approach to dementia care based on relationships between different people rather than one which effectively isolates each individual with dementia; as Bond (1999: 564) points out, ‘individuals do not function in isolation, they also have relations with others; all human life is interdependent and interconnected’.

Dementia theorists are also concerned to find out what leads a person with dementia to be excluded. This body of work focuses on how the self-identity of a person with dementia is slowly eroded by the language and attitudes of others. The way in which language undermines identity was the central theme of the seminal text *Old Timers and Alzheimer's* (Gubrium, 1986). More recently, a strong body of literature argues that the self-identity of a person with dementia remains intact, even when symptoms of dementia are severe, and that this process relies heavily on the attitudinal approach of others (Sabat and Harre, 1992; Sabat, 2001). These authors have found through empirical research that people are described or ‘positioned’ according to their dementia. For instance, if a person with dementia is observed walking around a building that behaviour will often be referred to as ‘wandering’ – as a sign of the ‘deterioration in social behaviour’ which clinicians regard as characteristic of dementia. Alternatively, with understanding of a person’s background the same behaviour might be construed as perfectly rational, for example, the person might be looking for a way to leave if they find the environment does not concord with their own sense of identity. Similarly, Small et al. (1998) argue that identity is preserved as long as a person with dementia is cared for with this possibility in mind. This work makes a significant contribution to understanding micro processes of exclusion; however, there remains a gap in knowledge as to what other factors (besides a ‘malignant social psychology’) contribute to loss of identity.

For example, what impact do class and gender have on an older person with dementia living in a care home? And are organisational values based on the concept of ‘choice’ appropriate for people whose higher cortical functions (such as calculation and comprehension) are impaired to varying degrees? These questions have so far been



avoided within dementia studies partly because of the preoccupation with gaining an insight into the experience of dementia (Binstock et. al 1992; Braudy Harris, 2002) and partly because micro-level explanations of any health condition have a tendency to ‘over-psychologize’ the individual (Clarke and Marshall, 2001:3).

Other studies interested in the reasons why the label ‘dementia’ should subsume the identity of a person with dementia pay closer attention to the negative effects of the process rather than its instigation. For example, Gilleard (1993: 152) theorises about the effects of cognitive impairment on the position that an individual with dementia has in society. In his view, as people with dementia become more and more dependent – much like children – this process of ‘losing one’s mind’ becomes synonymous with ‘losing one’s place in the adult world’. The fear of this happening was perhaps why most respondents to a quality of life survey for people with moderate to severe physical disabilities said that what they most valued was having control over their mind (Albrecht and Devlieger, 1999). The high value that Western societies place on cognition is noted in the dementia literature (Post, 1995, Brooker, 2003). However, few studies have sought to find out whether a person with dementia feels stigmatised or excluded because of this. Gilleard and Higgs (2002: 169) certainly believe that fading mental prowess is what contributes to the marginalisation of people with dementia from mainstream society, as they say:

‘The public failure of the individual to exercise control and the evident inability to effectively exercise such control excludes the person from participation as an agent within the civilised (social) world’

The infringement of peoples’ fundamental human rights on the basis of dementia is a deeply concerning issue (Dworkin, 1986). However, so far, those within the field of dementia studies have mainly dealt with this issue as a psychological rather than political problem. Finally, reviewing this area of literature, my argument is that that if the situation of people with dementia were politicised more rather than psychologised then wider influences unrelated to (or contributing) to poor care practices might also be identified and maybe even ameliorated. Moreover, it would also reveal the power that individuals with

dementia have to resist and reverse exclusionary processes related to a ‘malignant social psychology’.

#### **2.4 Growing old in a care home – sociological perspectives.**

Research into growing old in a care home is voluminous. However, little is known about what this experience means to an older person with dementia. Analysing literature in this field, the reason for this gap in knowledge is partly because traditionally, research into residential care services has primarily concerned with how the service functions for older people generally, as opposed to only being concerned with how it functions for older people with dementia (Townsend, 1962; Willcocks, Peace and Kellaheer, 1987; Bartlett, 1993; Peace, Kellaheer and Willcocks, 1997; Bland, 1997, 1999; Atkinson, 1998; Forder, Kendall and Knapp, 2000; Joseph Rowntree Foundation, 2000; Peace and Holland, 2001), and also because sociologies of ageing similarly explore the circumstances of older people generally, rather than the process of ageing with a dementia (Fennel, Phillipson and Evers 1988; Bond, Briggs and Coleman, 1993; see Arber and Evandrou, M et al, 1993). There is clearly a need for more studies to combine work from cognate disciplines including gerontology, dementia and disability studies and biomedicine in order to fully understand the position of an older person with dementia in a care home.

Closer scrutiny of this gap in knowledge reveals how some exclusionary processes are thought to manifest regardless of whether or not an older person has dementia or lives in a care home, that is to say, they are to with age, while others, it would seem, manifest *because* of dementia or care home life. In other words, as suggested in section 1.2 of this thesis, three influences compound, namely, age, dementia and group living, to play a major role in this group of peoples’ experiences of exclusion and inclusion processes. Section 2.3 of this thesis reviewed the dementia studies literature; in this section, the influential natures of ageing and group living are teased out and examined so as to identify how they alter the circumstances of someone with dementia.

One major explanation for why older people generally (regardless of living arrangement) become excluded from society is disengagement theory. Disengagement theory was

developed in the 1950's and the main argument underlying it is that, 'society withdraws from the ageing person to the same extent as the person withdraws from society' (Cumming, 2002). In this theory exclusionary and ageing processes become inextricably linked, as self-exclusion is seen as synonymous with growing older. While the theory offers some insight into why an older person may not feel inclined to take part in activities that they once enjoyed doing, disengagement has been widely criticised, mainly on the grounds that it claims to be a 'unitary and universal phenomenon' (Fennel, Phillipson and Evers, 1988). From a 'social exclusion' perspective the main criticism to be made of this theory is that it assumes widespread disengagement is not a problem for society.

Walker (1999) notes that there is a common tendency for health and social care professionals to treat older people as a homogenous group and to accept the exclusion of this group of people, particularly from decisions concerning their own health. The example this author gives is of older people being discharged from hospital, often having had little say in the matter or the care package arranged. Another example would be of older people with dementia having little choice or say in the care home that they move into; either because the care manager is the one in the economic position to make decisions about where that person should go (Netten, et al. 2001) or because a care home is unwilling or unable to deal with the psychological and behavioral symptoms of dementia that that person has (Cook et al, 2000). Therefore, it might be suggested, that rather than older people being treated in society as a homogenous group, processes and systems exist which actually create a subgroup of older people, namely older people with dementia. This point is further evidenced by a review of the gerontology literature, where the need to empower and promote the social inclusion of older people generally is arguably well established (Wells, 1991; Allen, Hogg and Peace, 1992; Barnes and Walker, 1999; Todhunter, 1999; Scharf et al. 2000; DoH, 2000). However, the right of an older individual with dementia to take part in decisions concerning their health seems to be less well developed or even accepted (Goldsmith, 1996; Harding and Palfrey, 1997; Woods, 2001). The Kings Fund Centre (1986) provides an explanation for this by drawing attention to the possibility that the less mentally able a person is to participate in the decisions that affect their lives, the more likely it is that the rights and needs of others take precedence. This is certainly a

concern that the Health and Social Care Change Agent Team have in respect of the development of mental health services for older people (DoH, 2003b:25).

As well as conflict between older individuals and health and social care practitioners, growing old is also said to create tension within a person. Work by Mike Featherstone and Mike Hepworth in the past decade has significantly increased our understanding of the internal dilemmas that an older person faces. The idea these authors' propose of the 'mask of ageing' whereby a person may look old but not necessarily *feel* old is a powerful one, which aids understanding of how an older person manages conflicting societal pressures and micro processes:

'The individual struggle to maintain a balance between the external stereotypes of age-appropriate behaviour and the subjective experience of the self requires considerable energy, tenacity and other resources' (Featherstone and Hepworth, 1991: 378).

These authors also reflect on how much harder, possibly even unachievable, the maintenance of self-identity is for a person with dementia:

'old age understood as senility is not so much a mask or disguise as an 'iron cage'. The self becomes imprisoned in a body which is no longer physically able to express its 'true' identity; the afflicted individual has lost his or her power of self control: of being able to express the self identity that he or she believes that others have come to expect' (Featherstone and Hepworth, 2001: 313).

As well as external processes and systems conspiring to create a subgroup of older people, the biological course of dementia would also seem to lead to an inequitable amount of what Cohen and Taylor (1992) describe as 'identity work' for individuals to do. The question is, which group of older people has the most work to do in order to maintain a sense of self? In one study, residents of a nursing ward who were asked to explain how they perceived the position of other residents with dementia discussed this issue. While many participants described the situation of others in negative way, some emphasised the benefits of being cognitively impaired such as, being released from the 'burden of the past and the premonitions of the future' and generally not having to worry about what other

people think of one's behaviour (Golander and Raz, 2001: 362). This highlights the fluidity and unpredictableness of exclusion process, and the need to investigate still further the experience of ageing with a dementia.

Historically, the lack of citizenship afforded to people having to live with other people dates back to the Poor Law days and workhouse system of social control when 'social deviants including the elderly poor were punished for transgressing conventional social norms' (Willcocks, Peace & Kellaheer, 1987: 17). Concerns about the poor conditions and lack of rights afforded to older people living in residential care have been consistently raised (Townsend, 1962; Meacher, 1972; Norman, 1987; Sixsmith, 1986). According to Peace, Kellaheer and Willcocks (1997: 114) the 1990's gave way to a 'new mood' about residential and nursing home care. This was due mainly to the development of standards and rights for people in this care setting (Smith, 1997). To date much of the research concerned with raising standards in residential care homes has been based on the circumstances of older people generally. This means that much is known about what older people in this situation need and have a right to expect such as independence, choice, to live in dignity and privacy and to have basic human rights safeguarded (DoH, 1989; DoH, 2001b). It also means though, that assumptions are made about what is important to someone who is cognitively impaired, as traditionally this group of people have been a 'silent and excluded voice' from the research agenda (Wilkinson, 2001). It might be, for example, that a sense of belonging and security are more important to a person with dementia than choice and independence (Martin and Younger, 2000).

The amount of literature on this subject also reflects concerns about the unknown cost benefits of this type of provision – for example, little is known about the effect of quality of care on people with cognitive impairment (Netten et. al., 2001). Because of the history and cost of residential care, much of the literature on this type of service provision is negative in approach and tone. This is probably also true to say of public attitudes towards it. Institutions have a 'poor image virtually everywhere in the world (Wilson, 2000); a large-scale survey of public attitudes to social exclusion across Europe found that 'living in a home for the elderly' was ranked as one of the signs of poverty (Golding, 1995: 218).

The reasons why living in a residential care home should be so undesirable are summed up by Fisk & Wigley (2000: 28):

‘(Older peoples’) lives, and the control that they can exercise over them, stand in stark contrast to their prior experiences. They become licensees in somebody else’s establishment and their world often shrinks to a room some 12 square metres in size. Outside that room, they are obliged to share space, meals and facilities with other residents. Entertaining visitors becomes problematic and control over the normal activities of daily life is substantially comprised’

Therefore, questions about the influences that this type of residence has on meanings of exclusion to older people with dementia and other people who live there, seem particularly pertinent to ask. However, equally as important, are questions about the positive meanings that communal living can have in later life (Nolan et al, 1996).

Reviewing this literature there are significant gaps in knowledge around the key points in an older person’s journey through residential care when exclusion and inclusion processes are most likely to occur. The first point is when a person moves into a residential care home. Peace, Kellaher and Willcocks (1997) examined studies of relocation and suggest that it is time of significant threat to self and to identity. There are a number of reasons for this. Moving into an unfamiliar environment; living alongside people you do not know (or perhaps do not wish to know); having to take on ‘permanent membership of a purely age-based category’ (Hockey, 1991: 216); changing life time habits and preferences in order to fit in with the routines of a new ‘home’. These are profound disruptions in anybody’s life-course and it is suggested that a change in home should be understood as a ‘potential disruption of the meaning of life’ (Norman, 1999: 75).

The potential for disruption is perhaps greatest for an older person with dementia moving into residential care. This is partly because the disruption in location that occurs – that is, having to move out of area away from family and friends (Reed, Roskell-Payton and Bond, 1998), is most likely to affect this group who often require specialist residential support which is in high demand but in relatively short supply (Wenger, Scott and Seddon, 2002). Also, the dementia care literature reveals how for someone already experiencing confusion

and memory related problems, moving into an unfamiliar and noisy environment like a residential care home is likely to be even more stressful (Marshall, 1996). However, perhaps the most significant reason for why such a move should particularly trouble an older person with dementia, is because individuals affected by dementia are unlikely to have been involved in the decision (Netten, 2001 et al.).

The second point in a person's journey through residential care when exclusion and inclusion processes are most likely to occur is as a person adapts to the new environment in which they find themselves. Clearly moving into and living in a residential home means different things to different people and so the process of transition will be an individual one (Oldman & Quilgars, 1999). That said, studies of peoples' transition to residential care suggest that many people attempt to adjust to their new environment by constructing for themselves a sense of familiarity and identity (Hockey, 1991, Reed and Roskell-Payton, 1996, Reed, Roskell-Payton, Bond, 1998). These authors identify an important influence in the social inclusion of older people in residential care home, as what they say is that other residents (rather than staff) have an important role to play in helping feel a part of the home. This finding is significant because virtually all dementia care studies focus on the role of staff (rather than other resident) in facilitating a sense of well-being and belonging (Kitwood, 1997, Jones and Miesen, 1992, Adams and Clarke, 1997; Cantley, 2001a, Brooker, 2003). While this is clearly an important avenue to explore it has meant the relationship between residents with dementia and residents without dementia has largely been ignored.

The significance of this gap in the literature is that we do not know how accepted people with dementia are in care homes which are integrated; neither do we know the extent to which the attitudes of other residents (as opposed to staff) influence meanings of exclusion and inclusion. Studies that do explore the relationship between residents suggest that it has the potential to be extremely oppressive and discriminatory (Meacher, 1972, Reed, 1999). Similarly, Netten (1993) found in her study of thirteen care homes that 'confused residents in integrated homes' were separate from other residents in the home; although the reasons for this were not explored or speculated upon (quoted in Redfern, 1997: 505). However,

relations between residents are not always considered negative. McKee et. al. (1999: 149) for example, reveals how cognitive (and physical) impairment can be facilitative as well as limiting of friendships. It may also be that there are gender differences in the relationships that people living in residential care have with each other. Given that housing solutions for older people are increasingly based on the inclusive notion of 'assisted living' for all (Hanson, 2001) dementia studies need to address this issue.

The physical environment shapes meanings of exclusion by making it more difficult for a person with dementia to find their way around (Kelly, 1993). Much is written about how aspects of the external environment (such as stairs) make getting about problematic for someone with a physical disability<sup>5</sup>. Similarly, the disabling aspects of an internal environment like a residential care home are well researched. Much more is therefore known about how best to design such an environment. Specific coloured carpets, for example, have been found to enhance way finding and orientation (Calkins, 1988) and well-lit, open-planned spaces corridors are thought to minimise confusion (Marshall, 1999). The growing significance attached to furniture and fittings reflects the wider recognition that barrier-free principals are seen as key to the promotion of social inclusion for people with a diagnosis of dementia (Marshall, 2001). Clearly this research is useful for architects and planners of new residential care homes. However, in the context of social exclusion often what is more important, and Marshall (2001) acknowledges this, is care practices (Blackman, Brodhurst and Convery, 2001).

Care practices are a major focus of the residential care literature. Studies of how staff look after and treat residents date back to the early 1960's when many new types of institutions were being built. This literature is particularly negative in approach and tone as it seeks to demonstrate how care practices within institutions have the effect of controlling every aspect of a person's life to the point that individuals living within them become completely depersonalised and dependent on other people (Goffman, 1968; Miller and Gwyne, 1972; Seligman, 1975). While these theories undoubtedly heighten our awareness of the potentially deleterious affects of certain care practices, they were formulated when it was



extremely uncommon for researchers to think of individuals as possessing agency – that is, as having the power and capacity to intervene in the world around them (Barnes, 2000). Modern studies of institutional life are therefore more likely to explore peoples' experiences of seeking control in an institution and to deconstruct notions of 'dependence' and 'independence' (Baldwin, et al. 1993; Johnson, 1993; Gibson, 1998).

It is argued that recognition of the degrees of interdependence, which exists for older people in any care situation; formal or informal, residential or community-based will improve the status of that group of people (Baldwin, et al. 1993). This may be particularly so for an older person with dementia in a residential care home who often relies on other people for considerable help and support. It is vital therefore, certainly from a health perspective, that people have an adequate sense of control (Rodin, 1986). Just as there are individual differences in the way that people adapt to living in a care home, there are variations in the desire for control (Nystrom and Segesten, 1994). Too little control for an older person with dementia in a residential care home can lead to an increased sense of frustration and 'anti-social behaviour' (Netten, 1993). Too much and they may decide to change the organisational framework of the home. This latter point is not meant facetiously but rather to highlight how much control a person living in a residential care home might potentially want, and why others may not want them to have any (Kontos, 2000). The issue of control is often discussed in the literature in terms of choice. It is argued that greater autonomy for people affected by dementia living in a care home could be brought about by increasing their day-day choices (Joseph Rowntree Foundation, 1999, Martin & Younger, 2000). At the same time for people with a diagnosis of dementia, who are increasingly living amidst a 'risk culture', real choice and opportunity may be denied on the grounds that they are assessed incapable of understanding the consequences of their decisions (Clarke, 2000). The real question then is not about how much choice a person has but how many opportunities a person has (Doyal and Gough, 1991). These types of issues have yet to be discussed within dementia studies.

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<sup>5</sup> This literature is reviewed in Chapter 3.

The third and final point in a person's journey through residential care when meanings of exclusion and inclusion are likely to manifest is, as and when a person seeks to take an active part in mainstream life. This is a crucial stage in terms of understanding the meaning of social exclusion and inclusion as it depends entirely on where and what 'mainstream life' is and constitutes for any one individual. For example, in most studies of social exclusion, it is assumed that people's frame of reference is their own home and that they are well enough and at liberty to fully participate in everyday life. However, the 'social space' in which people had been living is quite likely to have closed when they moved into residential care home (Norman, 1999: 78). Hence, for an older person living in a residential care home, who may be physically and mentally frail, a person might not want to go out as much or access to the outside world may be severely limited by resources (such as staff and transport) and as such that external world takes on an unreal quality; consequently people may shift their horizons to their living space which in turn becomes 'mainstream life' for them (Shurmer-Smith and Hannan, 1994: 41). The degree to which life in a care home is 'mainstream' is clearly debatable. Hence, one might suppose the concept of 'mainstream' needs to be problematised in any study of social exclusion.

## **2.5 Summary**

This chapter had set out the main rationale for this small-scale empirical study. Discussion has focused on two major areas of work: the social exclusion literature and dementia studies. The review has also stretched into other areas of sociological research as and when greater explanation or evidence was needed for the issues under scrutiny. The fact that this was necessary highlights not only the gaps that exist in the two major areas of work under review but also the potential there is for the cross-fertilisation of ideas and theories. The review has highlighted a number of significant gaps in knowledge about exclusion and inclusion processes and older people with dementia in care homes.

One of the most significant gaps in knowledge is our understanding of what social exclusion and inclusion mean in this context. Specifically, what factors contribute to the processes and how people affected by cognitive impairment experience these processes. So that an examination of exclusion and inclusion processes as experienced by older people

with dementia in residential care homes might be made, the following is a working definition of the phenomenon:

Social exclusion is a process whereby people gradually lose their status in the social world. It is characterised by a lack of meaningful opportunities and sense of identity and belonging. A complex range of factors including societal attitudes and health status influences the process.

In conclusion, personhood and the accompanying theory of dementia care as developed in Kitwood's research have had a profound influence on understanding the psychology of exclusion (Maciejewski, 2001). However, there is a still huge amount of work to be done in understanding the wider influences in peoples' lives (such as poverty and lack of education). As it might be that the main route to inclusion for an older person with dementia living in a residential care home is through recognition of their mainstream rights as citizens.

## CHAPTER THREE

### Study Background - the social model of disability

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#### 3.1 Introduction

The central aim of this chapter is to critically review the social model of disability. The primary reason for considering this particular lexicon of disability studies is because it offers a potentially convincing account of why people affected by impairment might be excluded from mainstream society. Discussion considers how the development of the social model has raised understanding about the meaning of disability at a personal, political and intellectual level, and how the model has improved the social and legal rights of persons affected by impairment. The chapter recommends the social model of disability, as a potentially useful paradigm and tool for understanding and improving the situation of older people with dementia in care homes.

The chapter is organised into three main sections. In the first section, changes in assumptions about the causes of disability are explored. This is where it becomes clear how definitions of disability impact on the position of persons affected by impairment and or chronic ill health in mainstream society. The second section sets out the main principles of a social model of disability. These are described in turn, thus allowing for a thorough examination of the model's theoretical contours. The first principle described is that of disabling social and physical structures, the chapter then examines attitudes and values as a factor in peoples' exclusion from mainstream activities. Finally, the disabling role of care practices and language is considered. The final section in this chapter reflects on modern developments within the field of disability studies. This is where the limitations of the social model are explored and arguments for a sociology of impairment are made. The chapter concludes by revisiting the main tenants of a social model of disability and asking what relevance such a framework might have for improving and understanding the lives of older adults who are cognitively impaired and living in a care home.

### **3.4 Shifting explanations of disability**

Chapter 2 showed how explanations of dementia are increasingly social (as well as biomedical) in origin and nature. In this section the wider move to explain disability in terms of a social phenomenon is outlined, and the implications of that paradigm shift on the position of disabled people are explored.

Disability is a phenomenon that has been defined from a number of different perspectives (Altman, 2001). The move to explain it entirely from a socio-economic perspective began in 1976 when the Union of the Physically Impaired Against Segregation outlined their fundamental principles of disability and critical thinking behind a social (rather than medical) model of disability first began (Tregaskis, 2002)<sup>6</sup>. Medical explanations of 'disability' were challenged at that time because of the threefold classification system upon which they were based. This system defined 'impairment' as lacking all or part of a limb, or having a defective limb, organ or mechanism of the body, 'disability' as the loss or reduction of functional ability' and 'handicap' as the disadvantage or restriction caused by disability (quoted in Oliver, 1993: 62). The problem that many people with a disability had with this model was that it focused entirely upon the limitations of the individual, regarded disability as an inherently abnormal and tragic state and took no account of the problems disabled people had which were caused by society (Oliver, 1996a).

As people with a disability increasingly sought to explain disability in their own terms rather than accept 'official definitions' upon which health and social care services had historically been based (Oliver, 1993: 62) explanations about disability became less medical and more socio-economic in nature and form. Reviewing the literature, this shift was marked by a dispensing of the view of disability as a personal tragedy about which society could do very little about, and replacing it with that of social oppression about which society could do a lot about (Oliver, 1996a, Barton and Oliver, 1996). The appeal of the word 'oppression' that it conveyed how people with a disability felt unable to carry out mainstream activities not because of mental or physical impairment, but because society was designed in such a way that privileged those without a disability (Priestly, 1999).

Introducing the notion of oppression into the debate about what disability means was a significant turning point, as it introduced the realm of politics. Political understandings of disability are important to track, as these ignited the Disability Movement and the change in legal status for people with a disability that the Movement eventually brought about. According to Johnstone (2001: 42) 'the law plays both an important symbolic and practical role in forming the ideological systems that legitimate specific sets of values and assumptions in society'. The Disability Discriminations Act (DDA) (1995) broadly defines disability as 'a physical or mental impairment, which has a substantial and long-term adverse effect upon a person's ability to carry out normal day-day activities' ([www.disability.gov.uk/dda](http://www.disability.gov.uk/dda)). A person with dementia is therefore 'disabled' as defined by the DDA. By the 1990's 'disability' was seen as a form of social oppression and definable by the lack of mainstream opportunities afforded to people affected (such as access to public transport and buildings and employment).

The wider cultural and political changes in thinking about disability have recently given rise to significant changes in the WHO classification system of disability. The new International Classification of Functioning, Disability and Health conceives of a person's functioning and disability 'as a dynamic interaction between health conditions (disease, disorders, injury etc.) and contextual factors' (WHO, 2001: 8). Thus, individual health factors are considered as one, but certainly not the only factor preventing people from participating fully in the social world. Classification changes of disability at a global institutional level mean that people with disability are less likely to be seen and treated in terms of an individual with an individual problem.

### **3.4 Introducing the social model of disability.**

As implied in section 3.3 of this thesis shifting explanations of disability have run in parallel with the development of the social model of disability. In this next section, the particular social model of disability that this study sets out to critique is briefly outlined and the three major theoretical contours that underpin it are introduced.

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<sup>6</sup> The principles of the social model of disability are described in detail in 3.3.

Gleeson (1999: 20) evaluates four different social models of disability and concludes that only one has had any major impact on British disability studies. The author describes that model as an 'historical-materialist' approach to disability as the developers were all inspired to varying degrees by the ideas and concepts of Marx and Engels. Given my stated interest in the power dynamics between the providers of residential care services for older people with dementia and those who use and depend on such services, it is this particular social model of disability that the study is biased toward.

Whenever dementia is discussed in terms of a disability, the discussion usually focuses upon the design of the social or built environment (Kitwood, 1997; Marshall, 2001). However, this understanding of dementia as a disability does not do justice to the full spectrum of ideas that the social model of disability has to offer. The development of a social framework for understanding dementia needs to also take account of the political environment, material resources and critically, subjective meanings of everyday situations and events (Bond, 1999: 566). The social model of disability in question was developed and formalised during the 1980's by a small group of mainly British disability theorists (Apperley Oliver, 1990; Barnes and Mercer, 1996; Barton, 2001). All these researchers contributed to a new framework for understanding disability which is known as The Social Model of Disability. The fundamental principle of the model is that society rather than impairment causes disabled peoples' problems. The model seeks to explain and remedy exclusionary practices that exist in all spheres of society from work to environmental design (Blackman et. al. 2003). The model therefore offers a radically different way of thinking about disability: it is based on the idea that rather than being 'caused by the functional, physical or psychological limitations of impairment' disability is in fact brought about 'by the failure of society to remove its disabling barriers and social restrictions' (Oliver, 1996a: 129). The model is essentially based on a rights-based approach to disability (Young and Quibell, 2000).

The fact that disabled people themselves are the driving force behind the development of a social model of disability reflects one of their most strongly held beliefs, which is that,

‘empowerment is not the gift of the powerful...empowerment is something that people do for themselves collectively...disabled people have decided to empower themselves’ (Oliver, 1996a: 15). This is an interesting global view of disabled people – have, and indeed can, *all* disabled people really decide to empower themselves? Certainly for people disabled by any degree of cognitive impairment, prescriptive accounts of how greater control should be achieved and who should instigate the process would seem to disable them still further (Adams and Bartlett, 2003: 15).

The social model of disability was never designed to explain disability in totality (Oliver, 1996a). It does, however, provide a useful tool to aid understanding of different aspects of disability (Llewellyn and Hogan, 2000).

### ***3.4.1 Disabling places***

One of the key principles of the social model of disability is that the physical world is an extremely disabling place for someone with impairment. When large groups of disabled people chained themselves to railings and buses during the 1980’s to protest about how difficult it was to gain access to public buildings and transport, the disabling aspects of the external environment were clearly demonstrated (Campbell and Oliver, 1997). The disabling aspects of physical environments are also widely discussed in the disability studies literature. For example, Morris (1993: 136) surveyed the internal design of homes provided for people with a physical disability and concluded that ‘unwanted dependence would disappear overnight if (disabled people) lived in a physical environment which did not handicap them’. In her view, local councils had very little (if any) knowledge of the particular housing needs of disabled people. Since then much work has been done within the field of disability studies to raise awareness of how disabling the physical environment can be for someone in a wheelchair (Gleeson, 1999, Hall and Imrie, 1999, Butler and Bowlby, 1995, Parr and Butler, 1999). Indeed, the DDA and further legislation planned, now makes it unlawful for certain public buildings not to be accessible for persons with a disability. The extent to which the physical environment precludes people with a disability from being able to move around freely has clearly become a major public concern.



While considerable work has been achieved in raising awareness of how disabling places can be, disability writers are 'silent' about cognitive impairment (Blackman et al., 2003: 367). The study by these researchers is unique in that it applies the social model of disability to people with dementia and asks how disabling the external environment is for this particular group of people. In particular, their work seeks to shift 'the focus from the disorientated, confused and distressed person, and the private sphere of personal medical tragedy, to the issue of disorientating, confusing and distressing environments, and the public sphere of planning and design' (Blackman et al. 2003: 364). As such, the study contributes not only to the social model of disability but also to related work in the field of dementia studies (Calkins, 1988, Marshall, 1997, 2001). However, questions remain unanswered as to whether or not the social model of disability might inform our understanding of the how spaces are culturally organised (rather than architecturally designed) to exclude people with a dementia from mainstream society.

Within disability studies this debate has been infused most significantly by the work of Kitchen (1998) and Gleeson (1999) both of whom argue for a closer examination of disabling spatialities. For Kitchen (1998) housing and educating disabled people in 'special' facilities perpetuates negative ideas and attitudes about disability. Therefore, this author argues for more inclusive social policies whereby people with a disability are treated as an integral part of human society rather than as a group who are different and 'out of place' (ibid: 343). Similarly, Gleeson (1999) sees the environment as an extremely disabling place for people with impairment, but that such exclusionary practices go unnoticed by non-disabled people and so people with a disability continue to be seen as inferior and different. (Morris, 1993: 59) explains how this happened in terms of the development of service provision:

'when the allocation of resources was placed in the hands of social services organisations and those working for them, they chose to spend large sums of money on segregated provision – which meant that disabled people had to live restricted and impoverished lives that the professionals concerned would never have chosen for themselves'

The relationship that people with dementia have with the state has yet to be properly explored. One of the few studies within the field of dementia care which sets out to investigate the issue of segregation and integration was by Meacher (1972). This is somewhat surprising given Government's relatively long-standing focus on the long term housing needs of older people (DoH, 1997, 2000). It means, though, that very little is known about how the practice of placing people with dementia in residential care homes shapes meanings of exclusion and inclusion.

### ***3.4.2 Disabling attitudes and values***

Another principal of the social model of disability is that certain values and attitudes are disabling to someone with impairment. Reviewing the disability literature, the two ideologies considered to be particularly disabling are those of 'independence' and 'caring'. According to Oliver (1993) the ideology of 'independence' is instantly disabling for someone with impairment because of the way that non-disabled people define it. For example, the definition of independence provided by the Audit Commission (2000) as an ability to self-care without assistance, is an accepted one. However, it means that a person with a disability who often has no choice but to constantly depend on other people for help and support with daily living activities then becomes defined as 'dependent'<sup>7</sup>. The concept of 'independence' thereby becomes a disabling one as it adversely impacts on a disabled person's experiences and identity (Priestly, 1999). The extent to which older people with dementia are 'victims of this ideology of independence' (Brisenden, 1998) has yet to be explored. From the perspective of someone with a disability, independence is better defined as 'the ability to be in control and make decisions about one's life' (Oliver, 1993: 54). This is also the finding of Baltes (1996) who undertook a psychological study involving frail older people in hospital and found that older patients delegated control to others as a way of 'reserving energy', thus maintaining and optimising the domains that they most value and are in most danger of decline. Anecdotal evidence from the dementia literature suggests that a person affected by cognitive impairment might also prefer a definition of independence which recognises the importance of being able to make

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<sup>7</sup> The negative associations with the term, 'dependency' are discussed in 2.

decisions about what areas of their life to 'let go of' and what activities are important to concentrate on (Davis 1989: 119).

The social model of disability is based upon the belief that values like 'independence' are important issues to unpack as they have the potential to stigmatise people who aren't able to do everything for themselves. Independence is a prominent feature of government strategy for older people with mental health problems (Audit Commission, 2000) and charitable organisations and older people themselves obviously regard independence as an important aspect of a person's life that should be maintained, regardless of age (Nystrom & Segesten, 1994). Thus, the question is raised, does independence have the same priority for people with dementia? Or are other possible care outcomes more important such as feeling safe or feeling a sense of belonging (Davies, Ellis & Laker, 2000). In considering the meaning of social exclusion these types of questions are obviously important to consider.

French and Swain (2001: 737) examine the relationship that health and social care professionals have with people with a disability and argue that it is based on an unequal power relation. In these authors' view such professionals maintain control over people with a disability by exerting unrealistic expectations such as to be 'independent' and for individuals to 'accept' their situation. Similarly, Drake (1996) objects to the way certain institutions impose their ideas of normality on to the people in their care; in his view dependency results not from the affects of impairment but by the 'organised altruism' of traditional charities. The principle written into the social model of disability that people with impairment are more disabled by the dominant values that surround them clearly has resonance with the situation of older people with dementia living in residential care homes.<sup>8</sup> And yet few studies have sought to examine whether or not this is the case.

The second ideology that people with impairment are thought to be disabled by is that of 'caring'. From a disability perspective, the main problem with a caring attitude and practice is that it can oppress people with a disability who may not want, and or have a say in the care they receive (Oliver, 1996a). Consequently, some writers suggest dispensing

with the ideology of caring, as it is as a form of oppression and expression of prejudice, and call instead for practitioners to recognise the negative impact that normative discourse generally has on the everyday lives of people with a disability (Morris, 1997, Ryles, 1998). Other writers with an awareness of the social model of disability have also explored the ways in which care is experienced as oppressive by a person with impairment (Swain and French, 1998); for example, being able to 'cure' people with the right type of care and treatment (Makin, 1995). While there has been some exploration within dementia care studies of the 'caring culture' and the oppressive affects it can have on an individual (Kitwood, 1997, Martin and Younger, 2000, Rundqvist and Severinsson, 1999). There remains scope for a more in-depth analysis of this issue using the social model of disability as an explicit guide.

The dominant paradigm of 'individualism' in health and social care settings is seen as 'a way of using power to oppress by separating each individual from the great body of humanity' (Ryles, 1999). The relevance of this may seem once again questionable in the context of people with dementia - would not any devaluing of individuality turn the clock back in dementia care to the days of simply 'warehousing' older people with mental health problems? However, the point that disability writers make, is not that people with a disability should be *cared* for as an homogenous group but that whilst practioners think of each individual as inherently different then the problems care recipients share are unlikely to be identified.

### ***3.4.3 Disabling language***

Another principle underpinning the social model of disability is that certain language and communication norms can be disabling for people with impairment. In the first instance, the issue of language reflects a wider concern within disability studies about the way that people with a disability are represented in modern society. For example, literary and film portrayals of 'hunchbacks' and 'cripples' as figures of fun and inherently villainous people, are said to contribute to the social stigma associated with a disability, (see Campbell and Oliver, 1997). Cultural representations of disability are important to note

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<sup>8</sup> See discussion in 2. ?

when discussing the disabling affects of language, as they constitute one of the main language sources for talking about and describing people with a disability<sup>9</sup>. For this reason, language is seen as both a 'cause and symptom of a disabling society' (Marks, 2001: 151).

The language used to describe people with a disability is said to be extremely hierarchical in nature and form (Johnstone, 2001). Terms and expressions such as 'care' and 'need' which derive from the medical domain often dominate descriptions of people with a disability. Moreover, the labels that the medical profession use to classify and describe people can have a profound affect on the status of someone with a disability. According to Hughes & Paterson (1997) the person becomes the political as the language used to describe them also often renders them docile, unproductive or disempowered. Certain modes of communication serve to exclude people with speech impairment in particular, as they allow people insufficient time or opportunity to express themselves (Booth and Booth, 1996, Paterson and Hughes, 1999). One of the long-standing aims of the social model of disability has therefore been to replace medically infused language with more politically charged talk of civil rights and identity politics (Anspach, 1979, Oliver, 1990, Charlton, 1998).

### **3.5 Modern developments in disability studies**

Modern developments within disability studies reflect the 'cultural turn' taking place within sociology generally (Nash, 2001). Disability theorists, like many others within the sociological field, are rejecting, or rather deconstructing tightly structured accounts of social life in favour of more relational and culturally based explanations. In this final section, the modern developments in disability studies which directly relate to and challenge the social model of disability are reviewed and used to provide evidence of the need for further theoretical work on the model.

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<sup>9</sup> The impact of popular representations of dementia on social attitudes has yet to be explored with quite the same vigour, although recent work by McColgan et al., reveals a welcoming interest in this area).

In the disability studies literature, one of the main criticisms of the social model of disability is that it fails to take account of either different groups of people or different types of disabilities. Fawcett (2000) and Morris (1993) bring a feminist structure to the debate about what people with impairment are most disabled by and find the social model of disability inadequate in its understanding not only of women but also of other social groups including children and people with mental health disorders. The main problem these authors have with the model is that because young white men with an ambulatory disability originally constructed it, the model has no basis in the experiences of the many other people with impairments. Consequently, modern challenges to the social model of disability often involve looking at how the model might be made more inclusive and relevant to the lives of *all* people with a disability (Crow, 1996).

For some, the best way of making the social model of disability more inclusive is by challenging the very assumption on which it is based. That is, the belief in an either/or medical or social approach to explaining disability. For Corker (1999) the binary opposition on which the social model of disability is based is problematic because it does not allow for any exploration of the space in between such as a person's emotional and bodily state. In a similar vein, Marks (1999a, 1999b) argues that many people with a disability are more oppressed emotionally than socially or politically and calls for a 'mutually constitutive' explanation of disability, as opposed to one that relies solely on the political and social context. An overriding problem with the social model, however, is that as much as it wants to not focus on impairment the reality is that individuals with impairment have to deal with it on a day to basis. As Crow (1996: 58) points out, 'the personal struggle related to impairment will remain even when disabling barriers no longer exist'. These ideas are crucial in the on-going development of the social model of disability; moreover, it means application of the model to 'new' groups and contexts (such as older people with dementia in residential care) have the potential to make a major contribution to a renewed approach to the social model.

The relevance of the social model of disability is increasingly examined in relation to other vulnerable and 'silent' groups of people with a disability such as younger people with a

learning disability (Chappel, 1997), children with physical disabilities (Llewellyn & Hogan, 2000), and more even more recently, people with mental health problems (Mulvany, 2000). Studies all take issue with the way in which the social model of disability completely ignores the issue of impairment in its analysis of disabled people lives. The ideological reasons for not focusing on impairment are that it would detract too much attention away from the barriers that exist in society (Oliver 1996). However, that noted, many disability theorists consider impairment and peoples' individual experiences of what it is like to be disabled, too important and central in a disabled persons' life to completely ignore. A study of the applicability of the model in relation to older people with dementia in residential care would therefore form part of this burgeoning interest in the multiplicity of disability and also contribute to the debate about the issue of impairment.

Corker (1999) highlights the limitations of the social model of disability from a postmodernist perspective. She explains how unhelpful it is to try and represent a person's life on the basis of a 'model', as if all aspects of that person's life are, knowable and fixed. Theorists who challenge the wisdom of ignoring impairment have begun work on a sociology of impairment (Hughes and Paterson, 1997). This particular development within disability studies is significant in that it challenges the very assumption on which the social model of disability is based, namely, that individual experience of impairment is irrelevant. Like others who criticise the social model of disability on this basis, French (1993a) sympathises with the originators of the social model of disability and their desire to keep the model simple and 'clean'. Nevertheless, she and many others believe that the only way to strengthen understanding of disability is by charting and analysing all aspects of it, including impairment and individual difference (Hughes and Paterson, 1997; Marks, 1999a, Mulvany, 2000). As Gleeson (1999: 20) points out there is a danger when shifting the emphasis of explanation from human deficiencies to social problems of neglecting the vital role that the body plays in the formation of human society.

While modern developments within disability studies have begun to address the problems and tensions of the social model of disability, a number of important questions remain about its usefulness for understanding the situation of those affected by a cognitive

impairment in later life. Not least of these is the question of what impact age and cognitive impairment might have.

### **3.6 Summary**

This chapter has evaluated a social model of disability. The basis of the review was that the model offers what seems to be a convincing account for why younger people with an ambulatory impairment are excluded from mainstream society. The model is based on a civil rights approach to social inclusion and believes that people with a disability are precluded from mainstream society not because of impairment but because of the way that society is physically, socially and linguistically organised. The ideas that the model is based upon are very similar to those within the field of dementia care studies. However, this model is developed by and for people with a disability and continues to be extensively theorised and developed. As such, there is a need for studies that seek to examine and expose the usefulness of the social model of disability for understanding and improving the rights of older people with cognitive impairment in residential care.



## **PART TWO**

### **THE RESEARCH CONTEXT**

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The goal of Part Two is to introduce and orient the reader to the study's methods of enquiry and also the places and the people that kindly agreed to take part. Chapter 4 provides a comprehensive overview of the methodological approach taken in this study and the variety of qualitative methods that were used to collect and analyse information. The many ethical aspects of this study are also explained and discussed here. Chapter 5 provides a fuller account of the places and people and that were involved in the study. The reader is introduced to the gatekeepers and study sites and also the sampling strategies that were used to identify participants. These chapters combine to provide the reader with the context for understanding subsequent chapters where empirical data are presented and discussed.

## **CHAPTER FOUR**

### **Methods of enquiry**

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#### **4.1 Introduction**

The aim of this chapter is twofold. To provide the reader with a comprehensive account of (1) why the questions were formulated and tackled in the way that they were and (2) the range of qualitative and analytical methods that were used to answer them. Given the breadth and complexity of these objectives the chapter will be divided into two major parts. Following a short discussion about the theory behind the methodological approach taken in this study, the first part of the chapter explains and presents the range of methods used to collect and analyse data. The second part of the chapter deals with the many and complicated ethical aspects of this study.

#### **4.2 Sociology and qualitative methods of enquiry**

The discipline of sociology has witnessed many debates about how social researchers come to know what they claim to know. Sociological arguments of this kind are clearly a philosophical concern as the very essence of human knowledge is deliberated and contested (Williams and May, 1996). In this study, the view is taken that we know what we know because we have some experience of it and have in turn attributed meaning or importance to that experience. This kind of ontological stance is in keeping with the interpretive tradition within sociology (Marshall, 2000). Interpretive sociology regards human (social) phenomena as inherently different from the natural world. That is to say, classic positivist preoccupations with ‘social facts’ and ‘universal laws’ are rejected in favour of an approach that recognises multiple realities rather than a single ‘truth’ and fluid perceptions of how things are rather than one fixed certainty.

Researching social phenomena within an interpretive paradigm means that the way individuals construct, manage and sustain social reality become of prime concern to the investigator (Gubrium & Holstein 2000). In this current study the assumption was made

that social exclusion could only be ‘known about’ or understood through the meanings that people attach to significant social actions (such as being cared for and going out) and the social model of disability could only be examined for relevance by exploring peoples’ subjective experiences of both disability, impairment and institutional life. Therein lies the fundamental reason for understanding and investigating the phenomenon of social exclusion in the way that this study has. It also explains why qualitative – that is, meaning seeking methods were the preferred tools for data collection.

One of the basic aims of qualitative research is to gain a thorough understanding of particular phenomena within certain contexts (Gribich, 1999). An accepted way of doing this within an interpretative paradigm is through close scrutiny of individual experiences and the meanings that people attach to these experiences. Schutz (1972) defined this as ‘the phenomenology of the social world’. In his most comprehensive work, Schutz (1972) coined the phrase ‘lived experience’ to emphasise the knowledge that people have of their social world. Schutz argues that lived experiences are sometimes common for different people and so a shared sense of reality can often develop and evolve. Although such inter-subjective experiences are often fleeting and fragmentary, they are nevertheless fundamental to social life (Campbell, 1981). One of the main attractions of interpretative phenomenology to this study is that it is not cognitively biased. That is to say, it does not presume that knowledge is only about what we think; feelings and emotions are important and given epistemic primacy and regarded equally as sources of knowledge. This is important, as people with a diagnosis of dementia are often thought to be more in touch with their emotional (rather than intellectual) self and sentience or heightened perception is often seen as a positive ‘symptom’ of dementia (Kitwood, 1993).

The goal of phenomenological research is not only to understand individual experiences of the social world but to also explore the meanings that different individuals attach to everyday life. It is this investigation of meanings that makes the understanding of social life possible. Phenomenological awareness was therefore a major ‘foundation of reality’ (Gribich, 1999:168) for this study, as understandings about social exclusion were located in the lived experience of participants, and explanations about how and why the process

was produced were based on interpretations of participant narrative. Of course the danger with gathering only subjective experiences of the phenomena was that the research questions would not be fully answered; for example, information about how social exclusion was produced would not be gleaned. Recognising the limitations of interpretative phenomenology the study looked to other traditions within sociology.

Combining methods is a popular practice within sociological enquiry; Denzin and Lincoln (1998) regard it as the best way for a study to gain both understanding of the research problem and credibility within the research arena. In a small scale qualitative study like this different approaches (and indeed data) were triangulated not in the navigational sense of the word – that is, to ‘fix an unknown point’ and so establish the ‘truth’ about the extent and nature of social exclusion in care homes. But rather, to understand the phenomenon of social exclusion by observing it from as many different angles as practically possible. As Hammersley & Atkinson (1983) state ‘the first requirement of social research is fidelity to the phenomenon under study, not to any particular set of methodological principles, however strongly supported by philosophical arguments’.

Given that this study was interested in not only the experiences of social exclusion but also the factors shaping the process, the study chose to combine a phenomenological methodology with an ethnographic type approach (Maggs-Rapport, 2000). Ethnography has a long tradition in qualitative research and like phenomenology the approach operates within an interpretative paradigm, as the exploration of meanings is crucial (Vidich & Lyman, 2000). However whereas phenomenology aims to understand personal experience of everyday life ethnographic type approaches are described as an ‘ongoing attempt to place specific encounters, events, and understandings into a fuller, more meaningful context’ (Tedlock, 2000). In other words meaning is derived from culture rather than what the researcher has interpreted it to be from the words of participant narrative (Maggs-Rapport, 2000). Hammersley & Atkinson (1995) argue that whilst the accounts of participants are valuable they do not in themselves constitute a full understanding of phenomena, as all accounts must be interpreted in the context in which they were

produced. This in turn allowed the study to make an important distinction between people's experiences of social exclusion and the things that impact on these experiences.

#### **4.3 Formulating the research questions**

Research questions constitute the most important element of any research design, as it is the answering of them that research activities are directed (Blaikie, 2000). Part One explained the significance of the research questions in relation to existing knowledge. The aim here is to briefly clarify the methodological and practical considerations that went into their formulation.

Generally speaking, the types of research questions asked in a phenomenological type study are meaning questions designed to elicit the essence of experience. And the questions

##### ***Box 3 - The research questions***

###### **Major Research Question**

- 1 What does social exclusion mean to older people with dementia in care homes?

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###### **Subsidiary Research Questions**

- 2 To what extent do economic, social and legal conditions shape meanings of social exclusion and inclusion?
- 3 To what extent does the organisational context of the care home shape meanings of social exclusion and inclusion?
- 4 To what extent do normal biological processes of ageing and ill health shape meanings of social exclusion and inclusion?

asked in an ethnographic type study are descriptive questions designed to find out about the values, beliefs and practices of a cultural group (Morse and Field, 1995). The challenge in this study was therefore to formulate questions that would generate understanding of not

only how social exclusion was encountered by individuals but also what factors produced and fuelled the process. This study followed the suggestion of Creswell (1998) and reduced the entire study to a single overarching question and several subsidiary questions. Box 3 sets out the research questions posed by this study. One major research question and three subsidiary questions were set for methodological and pragmatic reasons. The methodological rationale for the first major question was so that a general description of social exclusion would follow – that is, the question invited an explanation of peoples’ meanings of exclusion and inclusion. The subsidiary questions specified certain influences which may shape these meanings so as to focus the study.

As well as focusing the study the research questions were also designed to find out about something of which little is known – social exclusion as experienced by older people with a diagnosis of dementia. The second methodological consideration was therefore to use *what* questions. By systematically asking *what* (rather than *how* or *why*) the study could really focus on the nature of the problem rather than possible solutions (Blaikie, 2000) and in turn gain a deeper understanding of the phenomenon of social exclusion. Finally, a major practical consideration in the formulation of research questions was that the study remained tightly focused and thus achievable within the timeframe of a PhD. This is why the study was limited to answering four research questions and why each subsidiary question focuses on an aspect of everyday life considered problematic by the social model of disability.

#### **4.4 Overview of study design**

The primary objective of the study was to understand the meaning and dimensions of social exclusion experienced by older people with a diagnosis of dementia living in institutional care. A secondary objective was to explore the relevance of the social model of disability to this particular social group. Given how little is known about either the phenomenon of social exclusion or the applicability of disability studies in relation to people who experience cognitive (rather than physical) impairment the study is highly exploratory and necessarily complex in design. The study used multiple methods, different interview populations and data collection questions, and involved a total of five study sites.

In addition, the study was part of a larger project and so questions asked in the field were designed to meet the objectives of both studies. Researching a complex phenomenon like social exclusion within the parameters of a larger project adds further dimension to the study design. For example, two researchers were employed to conduct the study and so I did not personally collect all the data used in this study. The studies also had different outputs (the larger project was to produce guidelines for good practice) and so the same data was being collected for very different purposes. The aims and objectives of the larger project are outlined in Box 4. The overwhelming preoccupation for both studies was the extent to which people with dementia were involved in the mainstream activities that they wanted to be involved in. The larger project investigated the issue by focusing on actual decisions being made in a range of settings and by different people. This study explored the same issue but with the social model of disability very much in mind, and only with people in residential and nursing homes. The investigation was therefore very much focused on the attitudinal, environmental and personal factors shaping peoples involvement in mainstream activities.

As well as sharing a theoretical interest in the concepts of choice and control the studies were methodologically compatible - that is, they were designed using the same raw components. The first component, important to both studies was a comparative one. This study needed to be able to compare people's experiences of living in a care home because, as explained in Part One social exclusion is a relation concept. Thus, by interviewing residents without a dementia diagnosis, as well as residents with dementia the study could compare and contrast experiences of having choice and feeling in control. Talking to other residents also provided a valuable source of information about how well residents, who showed signs of cognitive impairment, were accepted within the care home.

Another component built into the overall research design was flexibility and creativity (Baker, 1999). These features were vitally important to this study for two reasons. First, the study was part of a jointly funded larger project and so relied on many gatekeepers for approval and access; a flexible approach to data collection was therefore needed in order to

complete it. Second, creativity was an important part of the study design, as data collection involved people with varying degrees of physical and cognitive impairment and so we were imaginative in our approach to ensure the richness and complexity of the lives of those we interviewed could be elicited (Stalker, Gillieard, Downs, 1999).

**Box 4 – Aims and objectives of the larger project**

**Empowering Older People With Dementia: Balancing rights, risks and choice.**

The purpose of this project is to explore how decisions are made for older people with dementia. That is, to identify the opportunities that exist for people with dementia to be involved in how they live, the barriers to realising these opportunities, and practices that can overcome these barriers. In particular, the research will compare the decision-making opportunities of older people with dementia living in different care settings, namely residential/nursing homes, sheltered housing schemes and private residences. The methodology is based on the identification of 'decision-making deficits' in the lives of people with dementia living in supported and residential settings, followed by the development of policy, procedural and practice guidelines for meeting these deficits. (Bartlett & Martin, 2000)

#### **4.5 Introducing the methods of enquiry**

It is clearly a methodological imperative that a study deploys methods that match the needs of the research questions. The methods used in this study were designed to understand the complex phenomenon of social exclusion in the context of dementia and residential care. Each part therefore begins with a short rationale for why that particular method was used, and how it matched the needs of the research questions. Discussion then focuses on the



sequence of events and the exact nature of activities undertaken. Methods are described here in the chronological order in which they happened. Theoretically, however, work could have been carried out in any sequence, as it was the *type* of information that each method generated that was important to this study rather than the order in which it was collected. Finally, the limitations of each method are acknowledged and discussed.

#### **4.5.1 Focus groups**

The focus group method is an interview with several people on a specific topic or issue (Bryman, 2001). They were used in this study to find out how care workers working in the study sites spoke and thought about residents with a diagnosis of dementia. The idea was that the dimensions of understanding that often remain untapped by the more conventional one-one interview could be more fruitfully explored within a group context (Kitzinger, 1994). Interviewing people in a group involves interaction between group participants as well as with the moderator, and so greater understanding could be gleaned about how care workers *spoke amongst themselves* about people with dementia. Indeed, it is the gathering of this kind of 'interactive data' that distinguishes the focus group from the individual interview (Wilkinson, 1998).

Understanding how care workers interacted with each other was important to this study as it provided valuable insight into the social world of care workers; *their* language and concepts, *their* frameworks for understanding things (Kitzinger, 1994). In addition, because group members asked questions of each other (perhaps more searching than those the researcher might have dared ask) and contradict and disagree with each other (in a manner which, coming from the researcher, might have seemed authoritarian) (Wilkinson, 1998) the social construction of ideas about normality and difference were exposed. Thus, focus groups produce less information on individual motivations and perceptions than individual interviews can achieve, but they yield additional information as people react to views they disagree with, or the group as a whole develops a perspective on something (Hakim, 2000). In other words, by conducting a small number of focus groups with care workers this study had a valuable access point for this study into some of the cultural aspects of care home life.

A total of three focus groups were conducted comprising care workers working in the residential homes at the time of the study. Given the practical problems of getting a group of busy care workers together at any one time, and to avoid disruption to the daily running of the care home the research team were flexible about who took part and when the groups were conducted. All care workers were therefore invited to take part and also reassured that they did not have to if they did not want to. A time and date for the focus group was then agreed with the home care manager and displayed on the staff notice board. The groups were all well attended - possibly because care workers had a rare chance to sit and reflect on care practices - and lasted for approximately one hour. Except for the senior carer at Encombe House who came in especially to take part in the focus group, attendees were all care workers on duty at that time. Appendix a details the composition of each focus group.

Despite the general recommendation that focus groups avoid hierarchies (Stewart and Shamdasani, 1998) this was not always feasible, or even desirable. The owner/manger of Durlston Court very much wanted to take part in the focus group and as she had already helped considerably in the study it would have been discourteous for us to not allow her. As it was her involvement proved analytically interesting as some of the care protocols that she thought were really important in promoting choice, junior care workers were not even aware of. The analytical aspects of focus group data will be fully discussed later in this section. The reader needs to be first aware of how the focus groups were conducted.

Each focus group was tape-recorded and facilitated by two members of the research team - one person moderated whilst the second person made notes<sup>10</sup> Focus groups took place in a private meeting room within the residential home where participants worked. A strategy for guiding focus group discussion was designed mindful of the fact that too much moderator control might prevent group interaction; too little control, and the topics might never be discussed (Agar and Macdonald, 1995). To facilitate and structure discussion a 'card-game' was therefore used rather than a conventional interview schedule or list of

questions. The 'card-game' was adapted from a quality lifestyles training pack designed to raise awareness about the way services are delivered to older people with dementia (Brown & Benson 1997). The training pack contained over one hundred statements. The statements were selected on the basis that they would provoke discussion about a broad range of social issues and activities (such as standard of services and trips out). Appendix b is a list of the eighteen statements selected and used in this study. The research team also hoped that selected statements would generate discussion of interest to group members (as well as ours) and thus engage people in a lively discussion in which members might then feel more comfortable sharing their experiences and opinions (Morgan, 1995)

The amount of cards used in each focus group varied depending on the amount of members. After the moderator had reminded members about the aims of the study and the purpose of the focus group, each group member was given two cards containing a statement. Members were then invited to read out what their card said to rest of the group, comment on how important they thought it was, and to then place the card in a pile marked 'important', 'not important' or 'unsure'. From the outset it was made clear to group members that there was no right or wrong answer to where the cards should be placed; the final layout of the cards was not important rather it was the process of getting there, which was revealing (Kitzinger, 1994: 104). The strategy was successful in as much as *all* focus group members said something about what decisions they thought residents with a diagnosis of dementia were and could be involved in, and what they saw as the key challenges in caring for a person with a cognitive impairment. Moreover, by using the same cards each focus group had an implicit structure and relevant issues *were* discussed in each group. This was useful given not only at the time, but my lack of experience of moderating a focus group. Also when it came to analysing data - a point that will be picked up again in the analysis section. They were of course limitations to using the 'card-game' and indeed to using focus groups *per se*; it is to these limitations that we now briefly turn.

The drawback of using the card-game to structure the focus groups was the lack of time this left for more spontaneous debate or dialogue. Because each group member had two

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<sup>10</sup> Transcribing was contracted out; I moderated two of three focus groups.

cards there was sometimes a tendency for group members to either rush discussion or perhaps feel disconnected from it (Morgan, 1995). In addition, the words in a few of statements were difficult for some group members to either read or understand (for example, *vatted*). The main limitation of focus groups as a method of enquiry is the possible problems of group effects (Bryman, 2001). For example, Fontana and Frey (1998: 55) highlight the possibility of an 'emerging group culture' interfering with individual expression. The use of the 'card-game' in this study helped overcome this.

#### **4.5.2 In-depth interviews**

In-depth interviewing is the hallmark of qualitative research (Rossman and Rallis, 1998). They were used in this study to explore how different people thought and felt about the opportunities available to residents with dementia to exercise choice and control. The technique belongs to a 'family of research approaches' that have one basic thing in common - conversation between people in which one person has the role of researcher (Arskey and Knight, 1999: 2). Broadly speaking, the role of the researcher in an in-depth interview is to initiate meaningful dialogue by asking a series of previously conceived well-crafted open-ended questions that are relevant to the study (Kaufman, 1994). The importance of investigating social phenomenon from the perspective of participants – in other words, from an emic perspective (Taylor and Bogdan, 1984) was discussed in section 4.2. of this thesis. The aim here is to explain the principles of in-depth interviewing and then to clarify why and how the technique was used in this study.

Part of the craft of in-depth interviewing is to actively engage the interviewee as a human being as opposed to simply regarding them as a study subject, as would be the case in a survey or structured interview (Kaufman, 1994). The methodological rationale for this level of engagement is to establish rapport and trust so that a deeper understanding of the participant's world (at least as far as they can and/or choose to verbally convey it) can be elicited. A first principle of in-depth interviewing is therefore for the researcher to see themselves rather than the interview schedule or topic guide, as the research tool (Taylor and Bogdan, 1984). In this sense an in-depth interview becomes an 'active interview' (Gubrium and Holstein, 1997) in that both the interviewee *and* interviewer are working to

make sense of things and to reach understandings. As Gubrium & Holstein (1997:114) go on to explain, 'meaning is not merely elicited by apt questioning, nor simply transported through respondent replies; it is actively and communicatively assembled in the interview encounter'. In other words, in-depth interviews cultivate a shared sense of meaning – or, in modern parlance, intersubjectivity (Denzin, 1998), which in turn has major implications for how the information that it generates is analysed.

In-depth interviews were an extremely valuable tool in a combined methodological study of this kind as they generated not only 'detailed, richly textured and person-centred information' (Kaufman, 1994) but also shed light on what was meaningful or important to an individual (Rubin and Rubin, 1995). However, as the interviewer also played a role in the construction of the interview – that is, meanings were co-constructed (Rossman and Rallis, 1998), when it came to analysis, interview transcripts were regarded very much as an artefact produced by a particular exchange in a particular context (Sapsford and Jupp, 1996). In other words, in-depth interviews were not used in this study so that generalisations could be made about the meaning of social exclusion in residential care homes, but to provide a platform for the analysis of exclusionary processes and encounters.

In-depth interviews were also used in this study for pragmatic and ethical reasons. First, as in-depth interviewing is an extremely flexible and accommodating technique. The approach can be - and indeed was - tailored to meet the different needs of a changing interview population (Rubin and Rubin, 1995). This was an important consideration given that in-depth interviews were conducted with older people, older people with dementia and also home care managers. In-depth interviews were also conducted with relatives; these are discussed separately in the case study section. Given these different sample groups, it was vital the study used a qualitative method that was not too specific or formulaic about what, or how things should be asked (as is the case in a life history interview, for example). In-depth interviewing allowed the researcher greater freedom to decide how best to approach and communicate with participants. Indeed, special techniques and procedures were used, particularly with participants who were cognitively impaired. However, these are deliberately discussed in a later section about training and supervision to emphasise the

point, which is strongly made in both disability and dementia studies, that the onus is on the researcher and not the researched to find ways to communicate (Booth and Booth, 1999, Goldsmith, 1997).

The flexible nature of in-depth interviewing also makes it an ethically sensitive method - that is, the technique recognises that respondents may appreciate some spontaneity during the interview (Bryman, 2001) or perhaps feel uncomfortable about being asked lots of questions (Pratt, 2002). This was an important consideration in this study, particularly as people with dementia are in a sense atypical research participants - that is, people affected are often not time-conscious or emotionally inhibited (Kitwood, 1997). Gathering information from them with an in-depth interview therefore seemed practically and morally appropriate. That said, it was also important that questions, which were asked broadly reflected the concerns of the study (Kaufman, 1994).

The study conducted three rounds of in-depth interviews. The first round involved 15 residents without a dementia diagnosis; the second, 12 residents with a dementia diagnosis and the third round involved 4 home care managers. A total of 31 individual interviews were therefore conducted as part of this study. Although the sample groups changed with each round of interviews, conversations were intended to be broadly about the same thing, namely perceptions of inclusion and exclusion, and where relevant, feelings of belonging and displacement. Of course, there was not always time to explore all of these questions in every single interview, as some people responded to the first question in one sentence, others spoke at length about the important things in their life. Rubin and Rubin (1995) therefore suggest that interviewers have a few main questions in mind and develop ways to gently move interviews along so that they can be asked. Appendix c highlights the main questions of each interviewee with dementia. Overall, the purpose of each interview was basically to understand what was what was important or meaningful to individuals (Rubinstein, 1988).

There were a number of limitations to using in-depth interviews as a method of enquiry in this study. First, the method is based entirely on language and so people with little or no

verbal abilities were unfortunately excluded. This meant the sample was biased towards residents who were able to verbally communicate and so the experiences of those who are perhaps most at risk of social exclusion (because they have lost their ability to verbally communicate) were therefore not accessed or recorded in this study.

#### **4.5.3 Individual case studies**

A case study is one of the most popular methods of social enquiry particularly when the research is small-scale and tightly focused (Denscombe, 1998). The case study method was used in this study to ‘catch the complexity’ (Stake, 1995) of social exclusion. That is to say, compiling detailed case studies with a few purposively sampled individuals was like examining the phenomenon of social exclusion with a specially built microscope.

One of the first points to clarify when discussing the case study method is what exactly it is you are studying – that is to say, what constitutes the ‘case’ (Burton, 2000). Given the major interests of this study the boundary or definition of a case was *an older person with dementia adjusting to life in a residential care home*. In other words, each case study investigated how people made sense of change and how they dealt with being excluded from their communities, aspects of social exclusion - and indeed dementia – where there was little existing research. The case study method in this project was therefore highly exploratory in design and type (Hakim, 1992). The case study was designed to be exploratory, as without this type of enquiry the study would have gained no sense of the social and cultural context in which human activity was experienced (Gillham, 2000). In other words, the case study method made the study design more robust by focusing on those areas, which could not be explored using in-depth interviews.

Each individual ‘case’ was regarded as an integrated system (Stake, 1995). In other words the experiences of people with dementia were studied holistically and in the context of social events and practices. According to Bond and Corner (2001) a limitation of the phenomenological approach to any study; but particularly to the study of dementia, is that the dynamics of everyday life are discounted in favour of member’s accounts. In other words, whilst it is undoubtedly important to ‘listen to the voices of people with dementia’

it may be that researchers can ‘get closer to reality by focusing on participants practices rather than their meanings’ (Bond and Corner, 2001: 113). A case study therefore provided a valuable opportunity to investigate not only what people said but also what they *did* (Silverman, 1997).

This brings us to the second important point to clarify when discussing case study method – that is, what and how are data used to build each case (Gillham, 2000). Reviewing the literature, theory is best generated from case studies, which use a diverse range of data sources (Blaikie, 1993). The idea was that each case would serve as a valuable 'building block' in the data collection and analytical process (Burton, 2000). The case studies used not only interview data but also documents and observations to provide a rounded and multidimensional account of how people were adjusting to life in a care home at the time of the study. A full account of the selection process and case study participants is given in Chapter 5. The important point to make here is that case study method is about the *quality* of the theoretical reasoning in which the researcher can engage rather than the *quantity* of data that is collected (Bryman, 2000).

As each case study was about building theory from the data rather than generalising to a wider universe, it was important that appropriate data were gathered, and used in a way that matched the needs of the research questions. The interviews conducted for the case studies were therefore slightly different in style and purpose than the other in-depth interviews, and documents were reviewed and observations made with particular aims in mind. The following is a *summary* of the general approach taken to case study work, individual variations and full particulars (such as who was interviewed and the different episodes of observation made for each case study) are detailed in Chapter 5.

Each case study involved interviews with a range of people, including the older person with dementia, their relative and a paid carer. As each older person with dementia had already been interviewed about their everyday experiences of care home life, case study interviews provided a forum for what was invariably a more relaxed and open conversation. That is to say, case study interviews were almost totally unstructured; at



most a mental *aide memoire* was used to remind the interviewer of any points to pick up on from the in-depth interview (Bryman, 2001). Re-interviewing participants in this way meant a more detailed insight could be gained into what they perceived to be important and meaningful in their life. The study was of the view that 'the experts in exclusion are the people who experience it' (MIND, 1999: 117). Generally speaking, case study interviews with participants were conducted in a different location (and ideally away from the confines of the care home) so that a participant might feel less inhibited about talking openly.<sup>11</sup>

Most interviews with relatives were conducted face to face and in their own home. This meant participants could talk freely and openly about 'the case' in their privacy of their own surroundings. In-depth interviews were conducted so questions could be asked about the events that led up to the participant moving into a care home. Extended contact with relatives also provided an opportunity to find out what the relative's impressions were of the care home; in particular what factors they thought impacted on their father or mother's ability to exercise choice and control. In-depth interviews with care workers were slightly different on a number of counts. First, they were conducted during working hours in a private meeting room in the care home. This meant interviews were relatively shorter and so less exploratory in nature. A series of questions were asked about the participant's typical day and the factors that the care workers thought impinged on their ability to exercise choice and control in their everyday life. In sum, each case study contained different accounts about how a participant was adjusting to life in the care home.

In addition to verbal accounts of participant's adjusting to life in a care home case studies also drew on documentary sources of information. Documents are widely used, particularly in ethnographic type studies, as they can tell a researcher a great deal about how events are constructed at the time, and the reason people have for doing things in the way that they do (Hammersley and Atkinson, 1995). According to May (1997:157) documents are vitally important to a social researcher because they are in a sense the 'sedimentations of social practices', which have the potential to inform and structure the decisions which people

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<sup>11</sup> A Consultant Psychiatrist suggested this strategy in the early stages of the study.

made on a daily and longer-term basis. There were obviously a wide and diverse range of documents that existed within each care home, and so it is extremely important to be clear about not only what documents were used to make up each case study, but also how the documents were used to inform our understanding of it (Bryman, 2001).

Each case study drew on two types of documents for two different sets of reasons. First, participant's private care records were accessed and reviewed. Care records are private documents, which care home staff are legally obliged to maintain – in methodological speak, they are official documents deriving from private sources (Scott, 1990). Thus, these written records inform future action, and are themselves fed into recording mechanisms of official statistics, performance indicators and similar constructs (Atkinson and Coffey, 1997). There are certain protocols to writing this kind of document (such as entries must be made in black ink, in case the record was needed for legal purposes and so had to be photocopied) and standardised forms are often used so similar information is recorded about each resident. As a resident's care records were confidential, consent to read them was required and gained from both the individual they were pertaining to and the home care manager.

Private care records were reviewed with two clear aims in mind. The first was to gather factual information about the participant (such as date of birth, date of admission to the home and medical diagnosis). This was useful for me, as it provided biographical information about the case study participant that might not have reliably be obtained from any other source. Quasi-facts (such as how often it was recorded that a person went out in the past six months and frequency/type of visitor) were also sought because a numerical measurement in each case study (Gillham, 2000) might in itself reveal something about the nature of exclusion from the wider community.

The second aim of reviewing a participant's private care record was to provide further contextual information concerning their everyday routines and care needs. A detailed review of participant's care records provided this by acting as a record of activities that I could not have observed directly (Stake, 1995: 68). It was also methodologically

important, however, that this study treated a private care record very much as a 'social product' to be examined rather than relied upon uncritically as a research resource (Hammersley and Atkinson, 1995: 168). Thus, the multiple and conflicting voices, differing language and interacting interpretations (Hodder, 1998) that were contained within a private care record served as another gateway into the cultural processes impacting on participant's ability to live an active and fulfilling life

The second type of documentary source used to inform each case study was gathered by myself and was used only for the purposes of this study – these were, public documents (such as national and organisational policies, care home brochures and inspection reports produced by Social Services Inspectorate). The rationale for gathering this type of information was to explore how institutional structures and procedures, and cultural processes impacted on a case study participant's ability to live an active and fulfilling life. Once again, a public document was regarded very much in terms of a 'social artefact' as something which needed to be critically evaluated rather than passively accepted as data. The series of questions that this study asked of documentary sources are outlined in Box 5.

**Box 5** ethnographic questions asked about text.

- 1 How are texts written?
- 2 How are they read?
- 3 Who writes them?
- 4 Who reads them?
- 5 For what purposes?
- 6 On what occasions?
- 7 With what outcomes?
- 8 What is recorded?
- 9 What is omitted?
- 10 What is taken for granted?
- 11 What does the writer seem to take for granted about the reader (s)?
- 12 What do readers need to know in order to make sense of them?

It was the answering of these questions that made for a stronger case study because only then could their role in relation to power and control be examined (Jupp and Norris, 1993).

#### **4.6 Thematic methods of data analysis**

The rationale and method for analysing the data using thematic techniques will now be clarified and explained. The decision to look for ‘themes’ *across* the data set and *within* each transcript and case study was based on this. (1) the search for themes and coherence is an activity rooted in everyday life, and therefore making sense of qualitative data in a thematic way has an intuitive familiarity and appeal (Luborsky, 1999). Indeed, the identification of key themes and patterns is the starting point for many analyses of qualitative data (Coffey & Atkinson, 1996) (2) a thematic-type analysis allows the analyst to proceed in a concept generating *and* concept-driven way (Gribich, 1999). In other words, thematic approaches expect concepts and models, which are relevant to the study, to guide and inform analysis. An important consideration given that a secondary aim of the study was to examine the conceptual principles underlying the social model of disability and (3) both baseline and case study interviews followed a conversational exploration of key themes (such as experiences of care home life and failing memory).

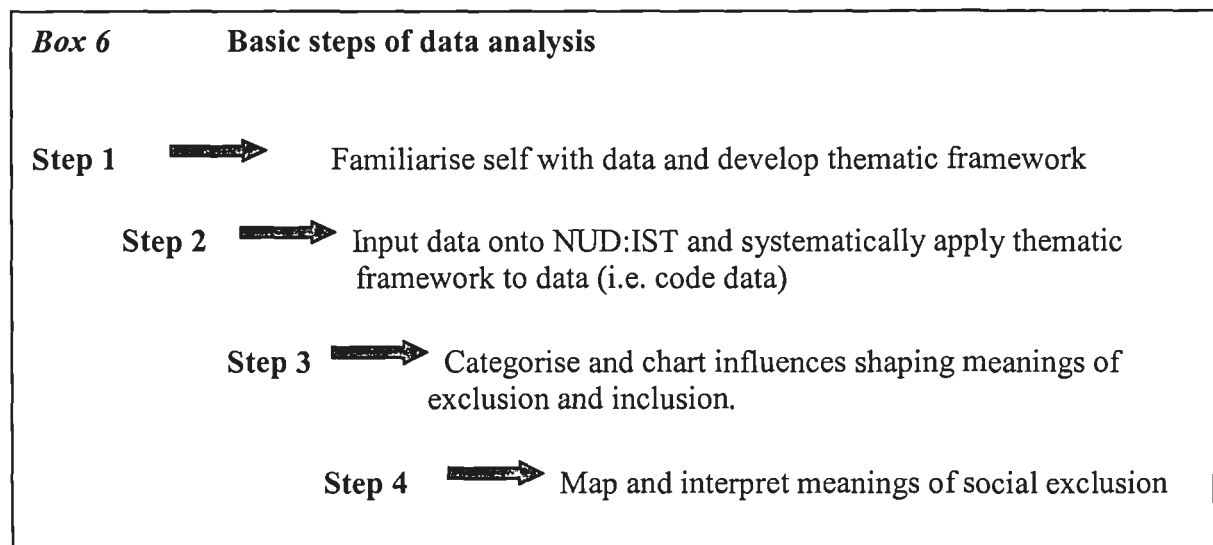
Another important reason for thinking thematically - rather than linguistically, for example, as is the case with conversation or narrative analysis - was that it does not presume, or necessitate a comprehensive or congruent ‘story’ with which to work with. This was an important pragmatic consideration given that other researchers have found that one must often be content with fragments rather than coherent narrative when talking with people with dementia (Killick 1998, Gillies, 2000, Procter, 2001). Finally, the study demanded an analytical position appropriate to the practical concerns of the study (Silverman, 1997) – namely, one that facilitated understanding of the meaning of social exclusion in this particular context. Thematic approaches achieved this by regarding data as ‘a window into human experience’ (Ryan & Bernard, 2000) and so the factors that shape people’s experiences of social exclusion and inclusion become easier to understand and

describe. In essence, thematic- type approaches were chosen as the best way of analysing this particular data set as they provide a pragmatic rather than prescriptive way of finding out about the nature of social exclusion experienced by older people with a diagnosis of dementia.

The goal of analysis was to find themes that both explain the research arena and fitted together in a way that I could understand (Rubin & Rubin, 1994: 254).

Thematic methods of data analysis typically involve coding, clustering codes to develop concepts or categories from the coding, and developing themes from these concepts or categories that help to explain the phenomenon under study (Coffey & Atkinson 1996).

Reviewing the literature there is a wide range of practical suggestions about how to actually do this. This study drew primarily on those suggested by Coffey & Atkinson (1997) Miles & Huberman (1994) Ritchie and Spencer (1994) and Rubin and Rubin (1994). Box 6 sets out the basic steps taken in the pursuit of themes by this study <sup>12</sup>.



#### 4.6.1 Familiarisation with the data set

The first step involved getting to know the data by immersing yourself in it; reading transcripts whilst simultaneously listening to the recorded interview, reminding yourself of field notes and diary entries, examining more closely daily care records and inspection

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<sup>12</sup> Data analysis was conducted completely independently of the larger project.

reports, and finally, reviewing observation notes and personal ‘hunches’. Given this volume of data (27 individual interview transcripts, 5 focus group transcripts, 4 sets of case study material plus additional personal reflections) I took the advice of Ritchie & Spencer’s (1994) and selected only a sample of data with which to familiarise themselves with. This sample included transcripts of interviews with the 6 male participants, 4 document reviews in addition to all the data I had not personally collected (1 focus group transcript, 11 individual interviews and 2 sets of case study material). In all, approximately 50 per cent of the data set was reviewed with the following objectives keenly in mind.

The central aim underlying the initial familiarisation process is basically a pragmatic one, namely to find out where important things were in the data. Except for focus group transcripts, which were given an inherent structure with the use of cards, qualitative data relating to one particular topic would not normally be found bundled together at exactly the same spot in each interview (Coffey and Atkinson, 1996: 35). As the study was interested in meanings of exclusion and inclusion, important or substantive comments were those, which related to where people with dementia could go, what they could do and the nature of social relationships. Explanations about *why* people thought or felt unable to do things were also regarded as important and marked with a highlighter pen at this stage. As a result of the familiarisation process, I gained what Miles and Huberman (1994) describe as an ‘initial intuitive analysis’ of the data- that is, the first seeds of conceptual development were sown by thinking about, and looking out for key themes and ideas from the outset.

#### **4.6.1 Applying the thematic framework to the data set**

The second basic step in data analysis involved applying the thematic framework to the data set. This is what Denscombe (1998) means by separating data into its component parts. Given the volume of data and my recent experience of NUD:IST it was decided to use this software programme to help manage the process of data analysis. NUD:IST is a computer programme designed to manage qualitative data, it is essentially based on a code and retrieve method of analysis and is characterised by two major components, namely a document and index system (Richards and Richards, 1998). The major advantage of using a computer programme to help with analysis was that all data for this study could be stored

and managed in one place. Consequently, this meant that basic string searches of the entire data set could be made quickly and reliably. For example, I searched the data set using the word 'home' to establish the locality of discussions about residence, loss and belonging.

#### **4.6.2 Charting and categorising data**

The third step in the analytical process was to categorise and chart factors which contributed to processes of social exclusion and inclusion. This essentially involved 'lifting' coded data from its original context and organising it, as a chart, according to certain themes or dimensions of social exclusion and inclusion. This process was undertaken manually in order that I retained a sense of the 'whole picture'<sup>13</sup>. Each chart contained a number of core categories and sub categories, in addition, the study generated a total of three charts in this way. The first chart captured data that revealed how wider social structures played a part in peoples' sense of social exclusion and inclusion. The second chart captured data that revealed how cultural processes played a part, and the third chart captured data that revealed what it was like for individuals to live in a care home. The main advantage of categorising and charting data in this way was that patterns and connections could be more easily identified. Hence, the final mapping and interpretation stage of data analysis would be better facilitated (Ritchie and Spencer, 1995).

#### **4.6.3 Mapping and interpreting data**

The fourth and final step in the analytical process was to map and interpret the contents of the three charts. Having reduced and simplified the data set, the final stage of analysis was to look *across* coded data in search of patterns and trends. Part of this process will involve 'testing out' preliminary claims by comparing the categories and sub-categories of different Charts. In addition, further claims will be advanced through writing about the significance of coded data and explaining why it should be of interest to others. The charts, (sub) categories *and* research questions may well need further refining as analysis progresses. The point of this final stage of analysis is to identify a structure - an argument- rather than

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<sup>13</sup> A criticism of NUD:IST as a qualitative software programme is that it can distance you from the data, and so 'hits' - that is, text that has been coded, is no longer seen in any context. Hence, the researcher used the system to store and help manage data, not to analyse it.

a 'multiplicity of evidence' and so there will be further sifting of data as the argument takes shape.

#### **4.7 Ethical aspects of the study**

Given the potential vulnerability of the research population, three important measures were taken to ensure that no harm came to either participant or researcher. These were gaining: formal approval for the study; informed consent from participants and training and support for the researcher team. These measures are now presented and explained in full.

##### **4.7.1 Gaining formal ethics approval**

The study required access to a vulnerable research population (older people and older people with mental health problems living in an institution) <sup>14</sup>. Therefore, before potential participants could be approached and invited to take part in the study, formal ethics approval was required from Local Research Ethics Committees (LREC) in the areas where homes - which had already expressed their willingness to take part - were located. This meant separate applications to two LREC's – one in the Southeast and one in the South. Both Committees granted approval of the study following minor amendments. The LREC in the Southeast, for instance, wanted us to also inform the participants General Practitioner (GP) of a residents involvement in the study, and the LREC in the South asked that the home care manager approached potential participants in the first instance to ask whether or not they minded being approached by a researcher. Once both Committees were fully satisfied that that the study would be carried out according to local ethical principles and protocols potential participants could then be approached.

##### **4.7.2 Gaining informal consent**

Potential participants were first approached and invited to take part in the study with the principle of informed consent very much in mind. In the following section the reader learns of the general approach taken in this study to gaining informed consent from participants (any extraordinary measures that were taken with particular participants are detailed in



Chapter 5 when a full account of the individual is given). The essence of the principle of informed consent is that a research participant should either agree or refuse to take part in a study in the light of comprehensive information about the nature and purpose of the research (Homan, 1991). The purpose of informed consent is therefore to safeguard participants' privacy and welfare, and to give them choice about whether or not to take part in a study (Arskey & Knight, 1999). I drew on ethical guidelines produced by the British Sociological Association (2001) to outline the type of information that participants should be informed about, namely what the research is about, who is undertaking and financing it, why it is being undertaken, and how it is to be promoted. The same guidelines also state how this should be done; as clearly and comprehensively as possible and in terms that are meaningful to participants. The onus is very much on the researcher then, to make sure that the people who have agreed to take part have been properly informed about the study and are truly willing participants.

For potential participants working in the study sites, gaining informed consent was a relatively straightforward and one-off event – that is, care workers were given information about the study, invited to discuss any concerns they might have had and then asked whether or not they would like to take part in an interview. However, for potential participants *living* in the care home, gaining informed consent was a more complicated and lengthy process. A number of factors complicated the process of gaining informed consent from potential participants who were residents. The first related to a question that has faced others in this field of social enquiry: should the word ‘dementia’ be used in participant information leaflets? (Crossan and McColgan, 1999, Gillies, 2000). The ethical dilemma researchers face in this situation is that to not use the word is to arguably not fully inform potential participants about the nature of the study. However, because participants may be unaware they have a dementia diagnosis, if it is used considerable harm/distress could potentially be caused (Bartlett and Martin, 2001). The research team chose not to use the word ‘dementia’ in any of the information leaflets; and like others (Crossan and McColgan, 1999, Gillies, 2000) we preferred and used the term ‘memory-loss’.

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<sup>14</sup> The larger project also required access to NHS staff. Joint ethics applications were made.

A second complicating factor related to where the study took place. Recruiting people within a care home environment meant that potential participants were reliant (to varying degrees) on care home staff. As Kayser-Jones and Koenig (1994) point out such a situation can interfere with true voluntary participation, as residents may feel coerced or obliged to take part and/or have a desire for human contact (even with a researcher) as a result of social isolation. To try and counteract this problem the research team distanced themselves from care home staff and emphasised their role as information-seeking researchers. For example, I deliberately positioned myself as a research student wanting to learn rather than as a former nurse (who might then be in a position to help or improve their situation). That said, during these initial encounters (and indeed throughout the data collection process) the interpersonal skills I had developed as a mental health nurse proved invaluable in gauging whether or not a resident was happy about talking to me, or wished I would go away as my presence bothered them. Potential participants were also approached in a relaxed and friendly way and without any expectations about them taking part. Appendix d is a copy of the information leaflet that was given to potential participants who expressed an interest at this stage.

Residents who expressed an interest and were willing to hear more about the study were sent a letter, which thanked them for their interest and set a date for another meeting. Appendix e is a copy of this letter. Two potential participants with a visual impairment were sent an audio version of this letter and the information leaflet. The next meeting with a potential participant was conducted in the privacy of his or her flatlet. This meant the conversation could remain informal and relaxed and in an environment that the potential participant was familiar with. Once again, it was emphasised how it was entirely their decision whether or not to take part and that they did not have to give a reason if they decided not to. Matters of confidentiality and privacy were also stressed at this stage; indeed people frequently asked how we planned to use the information. It was important therefore that the two main outputs of the research were clearly distinguished for potential participants (practice guidelines and a PhD thesis) and to make clear that neither these publications (nor any other reports) would contain either their name or the name of the care home. If at the end of this meeting a potential participant was still happy to be interviewed

they were invited to sign a consent form. Appendix f is a copy of this form. This was countersigned by a third person, usually the home care manager and subsequently filed for safekeeping.

A second major factor that complicated the consent process related to the cognitive impairment that was known to affect some participants in this study. As the study needed to conduct in-depth interviews and case study work with people with dementia the question of decisional capacity inevitably entered the consent process. Certain modifications were therefore made to the process of gaining consent when recruiting participants for the second round of in-depth interviews. These additional measures are now described.

Decisional capacity relates to a person's ability to comprehend information, deliberate choice and communicate with others (Kayser-Jones and Koenig, 1994). If stringently applied, as it is in medical case law (Law Commission, 1993) people with dementia would have to be discounted as potential research participants because legally speaking, if a person is cognitively impaired their ability to make an informed decision must also be impaired (Agarwal *et al.* 1996). Outside of medical case law, there is a growing trend that acknowledges the rights of people with dementia to have their consent sought (Downs, 1997). Moreover, the difficulties in assessing the capacity of the person with dementia to give consent to research (and care) are increasingly recognised (Killen, 1996). Researchers are therefore making greater efforts to find appropriate ways to include people with cognitive impairment in the consensual process to ensure that they too have their say (Mozley, *et al.*, 1999).

Agarwal *et al.* (1996) urge researchers to adopt a common-sense approach when attempting to gain informed consent from people with dementia. We therefore made a number of sensible adjustments to the consensual process for the second round of in-depth interviews. The first related to the pace at which information about the study was conveyed to potential participants. The research team appreciated that the cognitive impairment associated with dementia varies both within and between people (Stalker *et al.*, 1999) and so additional time was spent getting to know people when we first introduced to them by

the home care manager. This is when other researchers might have used a screening tool (such as the Mini Mental State Examination) to assess the cognitive ability of a person to take part in an interview (Mozley, *et al*, 1999). However, not only did our collaborating partner remove this option from us, having had experience of using the tool in clinical practice I felt it was inappropriate for a qualitative study of this kind, not least because of the inherent power differential that underpins a formal assessment procedure (Keady and Bender, 1998).

The second adjustment we made to the consensual process related to the involvement of a third party. Whilst not recognised in law, the assent of a representative is commonly regarded as an appropriate safeguard when informed consent of a research participant is not possible or considered problematic in some way (Medical Research Council, 2001). This study therefore assured both LREC's that as well as negotiating consent with a potential participant, one of their relatives would also be approached and asked for proxy assent - a requirement that was clearly explained to a potential participant during the initial interview with them. In most cases proxy assent was easily obtained from a son or daughter who visited most often, and whom the potential participant expressed no objection about me making contact with them.

The third and final difference in the consensual process for the second round of in-depth interviews related to how evidence of informed consent was sought from people with dementia. Like Bamford and Bruce (2000) we were concerned about asking potential participants to sign a written consent and perhaps cause undue anxiety, as people might recall signing an 'official form' but not be able to remember why. Therefore, like Bamford and Bruce (2000) we relied on verbal and behavioural consent and stressed that each participant was free to withdraw at any point during the first and any subsequent conversations. In short, we endeavoured to act in such a way as to preserve their rights and integrity as human beings, as 'such behaviour is ethical research' (Blumer, 1982)

#### **4.7.3 Training and supervision**

Although the study had been scrutinised and approved by LREC the research team recognised that they were ultimately responsible for protecting not only the well-being of participants (Orb et al, 2001) but also themselves (Lee-Treweek, 2000). In the penultimate section of this chapter the reader learns how the research team prepared themselves for fieldwork and made supportive supervision sessions a priority during data collection activities.

As well as gaining a post-graduate certificate in social research methods at the time of the study, I also learnt about how to conduct individual and group interviews from senior members of the project team. This more specialised form of training was designed to address my particular learning needs. Given the research population, the two main learning needs were identified as, communication and supportive group work. Hence, two workshops were organised around these themes and delivered to the small research team.

In addition to research training prior to fieldwork, I was also encouraged to use supervision sessions during data collection activities to talk through any unexpected or ethical issues that she faced. I found these less formal supervision sessions to be particularly useful when trying to recruit, and when compiling case study material with the second sample group (residents with dementia). The reason for this is because they provided a valuable outlet for discussing the emotional aspects of fieldwork.

## Chapter 5

### Places and People

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#### 5.1 Introduction

The purpose of this chapter is to provide further methodological and contextual information about the places and people that kindly agreed to take part in this study. A multi-site, multi-sample *and* multi-method study such as this can become difficult to examine and grasp intellectually, and so this chapter orientates the reader to where, when and with whom, data collection took place. More importantly for a phenomenological type study of complex design, the reader becomes fully grounded in the human (as well as the theoretical) context of fieldwork. Thus, by the end of Part II the reader should be aware of not only how and why information was gathered in the way that it was, but also the diversity of places and individuals that volunteered it.

The chapter is organised into two major parts. The first part introduces and describes features related to the places that were involved, including how sites were accessed and used and the physical and social features of each home. The second part provides a comprehensive description of the different types of participants, who were involved in the study, including: residents with dementia (especially those involved in case studies); other residents; care workers; and lastly professional staff members.

#### 5.2 Accessing study sites – an overview

Given the study's primary interest in understanding the qualitative aspects of social exclusion and inclusion in the context of older people with dementia in residential care, the study required access to a small number of residential care homes<sup>15</sup>. The number of study sites was less important to this qualitative inquiry than the diversity of residents who lived there. The eventual total of five study sites was therefore satisfactory for the exploratory purposes of this PhD study.

Before explaining how study sites were accessed, the reader may find it helpful to have a general sense of the types of organisations and individual care homes that were involved in this study. Three of the residential care homes (study sites 1, 2 and 4) were all owned and run by a large, not-for profit, housing, care and support organisation. This organisation is one of the largest independent housing providers in the country and offers a wide range of residential services to older people. This study accessed three of this organisation's residential care homes and so these three study sites shared a number of physical and social characteristics; for example, they were all modern purpose-built buildings, which could accommodate around 40 residents in individual flatlets. Study site 3, on the other hand, was owned and managed by a Registered Nurse. This home was therefore not only physically different from the homes run by the organisation, it also contrasted with them in a basic organisational sense. That is to say, study site 3 was based on the caring ethos of an individual (rather than an organisation) and so the management dynamics were noticeably different in this home. Study site 5 was different again in that it was the wing of a large nursing home catering specifically for older people with mental health problems. Furthermore, as it was owned by a large charitable organisation study site 5 also shared some of the organisational characteristics of those provided in study sites 1, 2 and 4.

All five study sites were located in the South of England within reasonable travelling distance from Oxford<sup>16</sup>. Gaining access to study sites 1, 2 and 4 was achieved with considerable help from a senior representative from the organisation. The senior representative started the 'access ball rolling' by distributing a memo to its Care Services Managers (CSM) in the midlands and southeast regions inviting them to contact the team directly about the research. As both studies aimed to be inclusive as possible and to maximise (rather than control for) diversity and variation, selection criteria were deliberately broad at this early stage. Two CSM's responded to our request for help and an introductory meeting was arranged. The purpose of this first meeting with gatekeepers was to provide senior management with additional information and reassurance about both the

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<sup>15</sup> Throughout this study, unless otherwise indicated, the term 'residential care' is used to describe both residential and nursing homes.

research and researchers, and to identify residential homes in their regions that could potential serve as study sites. Each CSM then contacted the care home (s), which had been identified. This was partly to give their 'official approval' for the research to be conducted, and partly to alert them to the fact that a member of the research team would be contacting them directly and in the very near future about the possibility of taking part in a study. As a consequence, access was successfully gained to study sites 1, 2 and 4.

As negotiations got underway with the care home managers of these homes, the proprietor of a specialist residential home had been identified in fortuitous circumstances. At the time of the study the department in which both projects were based hosted occasional public seminars. The proprietor of the specialist residential home that was to become study site four was a regular attendee. One week a member of the research team spoke to her about the project and the nature of the investigation, and she expressed a keen interest in taking part. This chance meeting was followed by a formal visit to the residential home by a researcher from both this study and the larger project. This not only gave the proprietor an opportunity to ask more detailed questions about the study, but also us a chance to share criteria for the selection of potential participants. Once both parties were satisfied that their respective needs could be met, work got underway to sample and access participants.

Access to the fifth and final study site - a wing of a nursing home - was equally opportunistic. As part of the larger project I visited a gentlemen on the assessment unit of a small psychiatric hospital. On the second visit he had moved to the 'physical wing' of a large private nursing home and so I went to see him there. Although this gentlemen was no longer well enough to take part in the study, during the visit the manager showed me around another part of the nursing home known as the 'East Wing'. This part of the nursing home was designated especially for older people with mental health problems; a large proportion of whom had dementia. During this visit the manager introduced me to three male residents whom she thought might be in a position to help me with the project. In essence, this was how access was gained to study site 5.

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<sup>16</sup> The location of study sites was determined by the timeframe and budget of both projects.



Overall then, the five study sites were accessed without encumbrance; once entry had been formally negotiated and sanctioned with senior managers and home care managers, the research team were able to properly familiarise themselves with each residential home, as a research environment.<sup>17</sup>

### **5.2.1 Study site 1 - Encombe House.<sup>18</sup>**

This home opened in 1990, and in common with most residential homes owned by the care provider, Encombe House was dual registered - that is, it accommodated residents with nursing (as well as social) needs. Each resident had a self-contained flat comprising of a lounge area with snack making facilities, bedroom area with built in double wardrobe, shower room and entrance hall with store cupboard. In addition, the large communal lounge incorporated a small shop selling everyday items such as confectionery, toiletries and alcoholic beverages. The home had large landscaped gardens and was surrounded by fields, although shops, a local post office and other amenities were nearby. The home was conveniently located in a quiet location on the outskirts of a major city.

A Registered Nurse, who had worked there since the home opened, managed the scheme and the large team of care workers and ancillary staff. The home care manager had designated an assistant manager to 'look after' my colleague and I and to co-ordinate sampling and administrative activities related to the study. During this introductory visit we were shown around the home and introduced to many of the residents and staff members. Certain physical aspects of the home were pointed out to us such as the colour of the walls, which was chosen by residents, and the spacious nature of individual flatlets. The fact that residents were free to come and go, as they pleased, was also highlighted. The overall impression gained from this initial visit was one of a clean, bright and welcoming place: the research team looked forward to researching there.

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<sup>17</sup> Formal permission to access the homes was also requested from and given by the Local Research Ethics Committee. This process is detailed in Chapter 4 of this thesis.

<sup>18</sup> Pseudonyms are used for *all* the residential homes to protect the anonymity of those involved.

Encombe House was a key study site in that it was used to gather a wide variety of data sources. For example, not only were individual and group interviews conducted with people living and working here, but also the provider's policy documents and guidelines were collected for analysis. Box 6 outlines the phases and amount of fieldwork that took place in this particular site. All data collection activities at Encombe House

<b>Box 6</b>	<b>Data collected at Encombe House</b>
<b>Phase 1</b>	1 focus group with care workers
<b>Phase 2</b>	9 in-depth interviews with residents
<b>Phase 2a</b>	1 individual case study
<b>Phase 3</b>	1 interview with home care manager
<b>Phase 3a</b>	Collection and analysis of relevant policy documents

were personally conducted, and so I came to know many of the staff and residents of that home very well. In all, I visited this study site on twenty separate occasions and spent approximately thirty hours of data collection time there. This included one overnight stay during Phase 2, as early evenings seemed to be the ideal time to meet and negotiate consent with the family of potential participants. Encombe House was therefore used very much as a 'fieldwork base' in that not only did I spend most of my physical time there, I also developed many of my conceptual ideas based on the events and experiences she observed.

### **5.2.2 Study site 2 - Lulworth Court**

The second site involved in this study was Lulworth Court. The home was also owned and managed by the provider in Study site 1. Therefore, it shared many of the internal and external characteristics of Encombe House, including a large communal area, small shop and landscaped gardens. This modern purpose built residential home was able to accommodate up to 40 residents on a permanent or short-stay basis. Located on the

outskirts of a large town, local amenities were nearby. A former Social Worker who, at the time of the study, had been in post for eight months managed the home. Like Encombe, the home employed around 40 staff, some of whom held a National Vocational Qualifications (NVQ) related to either care work or housekeeping services.

Box 7 sets out the phases and amount of fieldwork that was carried out at Lulworth Court. A colleague conducted activities in italics, and so personal contact and familiarity with this study site was notably limited. After the introductory visit, for example, I only returned

<b>Box 7</b>	<b>Data collected at Lulworth Court</b>
<b>Phase 1</b>	1 focus group with care workers
<b>Phase 2</b>	<i>8 in-depth interviews with residents</i>
<b>Phase 2a</b>	<i>1 individual case study</i>
<b>Phase 3</b>	1 interview with home care manager

to Lulworth on two more occasions, once to help moderate the focus group and once to interview the home care manager. For these reasons, Lulworth Court was used in this study in a slightly different way from Encombe in that the home simply served as a physical location and social context for interpretations of interview data.

### **5.2.3 Study site 3 - Durlston Court**

Durlston Court was the third study site used for fieldwork in this project, and it differed considerably from the other homes described so far in a number of respects. In the first instance, it was registered to accommodate twenty-two residents with mental health problems; therefore there was not a 'mix' of residents, as had been the case in Encombe House and Lulworth Court plus the home was notably smaller in size and capacity. In addition, Durlston Court was owned and managed by a Registered Nurse who converted her own home into a residential home in the early 1980's. The physical characteristics of

the home were therefore quite unique with many features in keeping with the style of a traditional large family home. In the kitchen, for example, was a large working agar and the lounge boasted an inglenook fireplace. Other internal features of the home included three communal sitting areas and a mixture of single and double rooms. Outside, the home was situated in a quiet rural location with local shops approximately five miles away. As Durlston Court was located on the main road of a small (but busy) village the home operated a 'locked gate' policy. That is to say, residents were able to come and go as they pleased around the grounds, but for their own safety the outside gate was permanently secured with a combination lock.

The other major difference with this study site was that Durlston Court was very much a 'women's world' in that at the time of the study *all* residents and staff were female (Peace, Kellaher and Willcocks, 1997). Staff worked part time flexible hours and individualised shift patterns (for example, one care worker was employed to work one night a week, another worked from 1700 – 2000 hours three days a week). A second Registered Nurse employed in the home worked full-time and deputised for the proprietor in her absence. However, because Durlston Court was registered as a residential home rather than a nursing home, neither Mrs. Davies nor her deputy actually carried out any nursing duties. The full range of data collection activities that took place at Durlston Court is described in Box 8.

<b>Box 8</b>	<b>Data collected at Durlston Court</b>
Phase 1	<i>1 focus group with care workers</i>
Phase 2	<i>3 in-depth interviews with residents</i>
Phase 2a	<i>1 individual case study</i>
Phase 3	1 in-depth interview with home care manager

A colleague working on the larger project conducted activities in italics and I only visited this home twice, once to pay an introductory visit and once to conduct an in-depth interview with the home care manager. Fewer interviews were conducted in this study site because there were fewer residents. The home also hosted one of the three focus groups, the composition of which is described in a later section.

#### **5.2.4 Study site 4 - The East Wing**

The East Wing was markedly different from the other four study sites in a number of respects. First, it was a nursing home rather than a residential home, and so every resident had been assessed, as having nursing needs rather than only social needs. Second, the East Wing inadvertently became a study site – that is, unlike the other four study sites, where residents were sampled *after* the home had been identified, in this instance, the participant had in effect been identified *before*, or at least at the same time as the study site.

The East Wing accommodated 30 residents with mental health nursing needs. Therefore the staff team included Registered Nurses, all of whom had been trained in the mental health needs of older people, and care workers. The home had a policy of recruiting nurses from overseas; hence, around 80% of trained staff were from a Far East country. A large team of care-workers supported the 12 Registered Nurses who were employed in the home. Residents were accommodated in single rooms on two floors. Downstairs, where the one participant who was sampled from this home resided, there was a communal area and separate dining room, an activities or ‘music’ room, which had patio doors to the small fenced garden area and of course shared toilet and shower facilities. The layout of the home was essentially one long corridor with each of these areas and bedrooms feeding into it

#### **5.2.5 Study site 5 - Purbeck Lodge**

The fifth study site was managed by the providers in Study sites 1 and 2. Like Encombe House and Lulworth Court the home had been purpose built to accommodate around 40 residents in their own self-contained flatlets. General facilities within Purbeck Lodge were

also typical of the provider with residents having use of a large communal area, small shop and bar, activities room and hairdressing salon. In addition, a small section of the home had been designated as a 'respite wing' and some residents only stayed at Purbeck Lodge on a short-stay basis. The home was located on the outskirts of a large market town, which meant local shops and amenities were nearby, although difficult to walk to given that the home was situated at the top of a small hill. In terms of staffing, Purbeck Lodge was managed by a former social worker who at the time of the study, had been in post for two years. An assistant manager and large team of care workers supported her. Considerably less fieldwork was carried out at Purbeck Lodge than the other two homes managed by the provider, mainly because at the time of the study there were no residents with dementia well enough to take part. This meant that only five 'other residents' were sampled from Purbeck Lodge.

### **5.3 Sampling participants – an overview**

Given the multi-dimensional nature of social exclusion and the study's methodological concerns with understanding it from as many different angles as possible, the study accessed more than one type of participant. In the first instance, due to the comparative element built into the design of this study, two types of residents were identified and sampled, namely residents with dementia and other residents not thought to be cognitively impaired. The third and fourth types of participant were care workers, and people with professional experience of residential care. Except for an Environmental Health Officer in the last group, all participants were selected from people living and working in one of the five study sites. In short then, the study used a total of four sample sources and deployed 'combination or mixed sampling' as the main sampling technique – that is, participants were selected on the basis that they met the multiple interests of this study (Miles and Huberman, 1994). The following sections are intended to furnish the reader with the particular characteristics of each sample group and to highlight when and why a slightly different sampling technique was used.

### **5.3.1 Sample group 1 – residents with dementia**

A total of 12 residents with dementia were identified and interviewed for the purposes of this study. Entry criteria for this sample group were: a diagnosis of dementia, aged 65 years and over, no recent changes in co-morbidity or receiving regular hospital treatment; and of course, a willingness to participate. Residents were identified in the first instance with the help of care staff. The home care manager (or care worker delegated to the task) was provided with a general overview of the sort of resident that we wished to interview. In this sense the home care manager or designated care worker acted as principal gatekeeper to participants. As well as the above entry criteria, the gatekeeper was also asked for mix of male and female residents from a range of socio-economic backgrounds. This sampling process, which was conducted in study sites 1, 2 and 4, generated a list of three, four and seven residents respectively. Accessing participants who lived in a care home was therefore achieved very much in co-operation with gatekeepers, and so the personal opinions of gatekeepers also entered very much into the sampling process (Fisk and Wigley, 2000). In this study for example, staff tended to suggest residents who they thought would "love to talk"; the methodological implications of which were discussed in Chapter 4, the point to make here is that even with an entry criteria, gatekeepers had as much (if not more) control over the selection of participants as we did.

Armed with a list of potential participants then, I approached residents casually and asked them whether or not they would like to take part in the study. I explained to potential participants as clearly and concisely as possible what taking part would involve and that if they weren't interested it didn't matter. These basic points were repeated as often as necessary and managed to filter out those on the list who were not willing to participate. Essentially this was how the 12 participants with dementia were selected for interviews. Figure 1 shows the general characteristics of sample group 1. In line with the general composition of the national care home population, females participants outnumbered male participants by 5 to 1 in this study. Interestingly, occupations of the sample group did not fall into gender stereotypes. The former RAF Officer, for example, was female, as was the publican; both men in this sample group worked in the car manufacturing industry, a major employer in the area. The majority of the sample group was widowed, with only 3

participants still married. The marital status of one woman was not clear as neither home care staff nor the participant herself knew whether she divorced her husband or he died. Most participants had a recorded diagnosis of Alzheimer's type dementia in their case note and most had sold their homes to fund their care.

From this sample group, four participants were purposively selected to build a series of individual case studies about adjusting to care home life. All participants were therefore asked at the end of the first in-depth interview whether or not they would mind if I came back to talk to them some more about their experiences of care home life. Those participants who declined or who showed signs of agitation at the prospect were excluded from the sampling frame at this stage. From the remaining members of the sample group, participants for the case studies were purposively sampled - that is, they were 'hand-picked' for the case study because of their particular experiences of social exclusion and inclusion (Denscombe, 1998). Individuals were selected not because they were typical or representative of other cases (other individuals with dementia) but because they were intrinsically interesting in their own right (Stake, 1995). The aim of the following subsections is to provide the reader with a more detailed biographical picture of the four participants who were involved in each case study.



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<i>Gender</i>	
Female	10
Male	2
<i>Occupation</i>	
Housewife	3
Factory worker	3
Teacher	2
Milliner	1
RAF Officer	1
Publican	1
<i>Marital status</i>	
Widowed	8
Married	3
Not clear	1
<i>Type of dementia</i>	
Alzheimer's	9
Vascular	2
Lewy Bodies	1
<i>Socio-economic status</i>	
Privately funded	8
Local authority	3
<i>Age</i>	
Range	68-91
Mean	79

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**Figure 1**      Characteristics of sample group 1 - residents with dementia

#### **5.3.1.1 Case study 1 Mrs. Green<sup>19</sup>**

At the time of the study Mrs. Green was seventy-seven years old and had lived in Durlston Court for almost one year. Mrs. Green had spent most of her married life living in a nearby town where she owned and managed a small bookshop. She had one daughter who was a nurse and whom she saw regularly. Her son died in a car accident when he was forty. During her retirement, Mrs. Green enjoyed traveling with her husband and taking part in local clubs and community events, particularly those organised by the University of the Third Age. Prior to admission she lived at home with her husband in a three bedroomed detached house and had been diagnosed with Lewys Body dementia two years previously.

According to the proprietor of Durlston Court, Mrs. Green moved into the home at the request of her husband and Community Psychiatric Nurse (CPN). Apparently he had been finding her behaviour increasingly difficult to cope with and manage on his own. Therefore, he had asked their CPN for help to find a suitable residential home for his wife, after much searching they settled upon Durlston Court. Mrs. Green's care was being paid for by their own income. Mrs. Green was selected as a case study participant, as I soon became aware following discussions with both the proprietor and Mrs. Green herself, that this lady would make for an interesting 'case' about social exclusion.

#### **5.3.1.2 Case study 3 – Mrs. Clarke**

At the time of the study Mrs. Clarke was 82 years old and had lived at Lulworth Court for 12 months. She had been widowed for one year and had one daughter and grandchild; both of whom lived in America and so she had not seen them for some time. Mrs. Clarke had spent most of her married life working in a biscuit factory. According to the key worker, Mrs. Clarke was a very 'sociable women' who used to enjoy organising fund-raising events for her local church and taking her dogs on long walks. The local authority funded her care.

According to her care records, Mrs. Clarke was admitted to Lulworth Court because care workers were having difficulty gaining access to her home and persuading her that she

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<sup>19</sup> The names of these, and all subsequent participants have been changed to protect peoples' identity.

needed their help and support. Mrs. Clarke was also recently bereaved which led social services to believe that she was having difficulty adjusting to life on her own. In addition, Mrs. Clarke was often awake at night, disturbing her neighbours. The staff of Lulworth Court already knew Mrs. Clarke, as she had been in their care for respite and day care. Mrs. Clarke was selected as a case study participant as early analysis of her interview transcript suggested to me that she was not entirely happy where she was living and lacked either the financial or personal resources to do anything about it.

#### **5.3.1.3 Case study 2 – Mr. Brown**

At the time of the study Mr. Brown was eighty-four years old and had lived in the East Wing for five months. Mr. Brown spent all his life in the same small English town. He left school at fourteen having not learnt how to read and write. He spent all his working life on the assembly line of the same car factory. Mr. Brown had one son from his first marriage and a stepdaughter from his second marriage. Prior to the onset of dementia, Mr. Brown enjoyed gardening and going out for a drink with one or two close friends.

According to his stepdaughter, Mr. Brown managed to live successfully on his own for two years following the death of his wife. However, she became increasingly concerned about her father's mental health and ability to look after himself when he started to telephone her in the middle of the night to ask her things that she knew he already knew. A social worker became involved and as his confused state worsened, Mr. Brown was eventually admitted to a local authority residential home. The home was situated directly opposite his stepdaughter's house, and as she did not drive this meant she was still able to see him on a daily basis. Unfortunately, the home proved to be unsuitable for the needs of Mr. Brown, as he would often leave the home and lose his way in the local town. Soon after his admission therefore, Mr. Brown was transferred to a hospital ward where his long-term care needs could be properly assessed. Following a short-stay in hospital, Mr. Brown was admitted to the East Wing, a nursing home approximately 10 miles away. Mr. Brown was selected as a case study participant, as his recent experiences of being excluded from one home and transferred to another were of particular interest.

#### **5.3.1.4 Case study 4- Mr. Smith**

At the time of the study Mr. Smith was seventy-eight years old and had lived at Encombe House for sixteen months. According to Mr. Smith, he moved into the home on the advice of his sons; during our first interview he described how his sons “coaxed” him into staying, although he said how he likes the home very much. Before moving into Encombe Mr. Smith had been living alone in a warden-controlled flat, however, his failing memory and increasingly poor eyesight meant that his sons grew increasingly concerned about his ability to look after himself.

Mr. Smith was born in 1924 and grew up in South Wales. He had no siblings. He married when he was twenty-four and spent most of his working life as a factory manager in the car industry. Mr. Smith used to spend a lot of his time reading and spoke at length during our interviews about how he missed his wife’s company and *joie de vivre*. Recently however, his eyesight had got so bad that he was no longer able to read and so he spent most of his time in the care home either making friends and chatting to people or reminiscing about the good times he spent with his wife.

Mr. Smith was selected as a case study participant from the small group of residents who were interviewed at Encombe House. He was chosen primarily because I wished to explore further with him his particular experiences of adjusting to care home life: Mr. Smith not only had a diagnosis of dementia he was also registered blind. Mr. Smith was also more than happy for me to interview him again, and to speak with his care worker and son about his experiences of living in a residential home. He was therefore, both an ‘intrinsically interesting’ and willing candidate with whom to build an individual case study with.

#### **5.3.2 Sample group 2 – other residents**

A total of 15 other residents who were not thought to be cognitively impaired were also sampled and interviewed for this study. Entry criteria for this group were essentially the same as they were for residents with dementia, namely: aged 65 years and over, no recent changes in co-morbidity or receiving regular hospital treatment; and of course, a willingness to participate. The main exception was that this sample group only included

residents who were not *thought* to have dementia. That is not to say, participants were definitely not cognitively impaired but simply that they did not have a diagnosis of dementia. Figure 2 provides an overview of the general characteristics of sample group 2. Like the other sample group, there were more women than men. The two residents, who were married, were married to each other.

The mean age of this group was marginally higher, perhaps due to the reduced life expectancy associated with a diagnosis of dementia (McKeith and Fairburn, 1997).

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<i>Gender</i>	
Female	12
Male	4
<i>Occupations</i>	
Nurse	2
Bus driver	2
Book-keeper	2
Housewife	2
Secretary	2
Florist	1
Cleaner	1
Caretaker	1
Sailor	1
Business man	1
Machinist	1
<i>Marital status</i>	
Widow	14
Married	2
<i>Age</i>	
Range	69-97
Mean	84

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**Figure 2**      Characteristics of sample group 2 – other residents

### **5.3.3 Sample group 3 - care workers**

The study accessed care workers for one of two reasons: either to take part in a focus group, or to be interviewed in connection with an individual case study.<sup>20</sup> In each instance, participants essentially selected themselves - that is, the study deployed a strategy of voluntary sampling when it came to care workers (Blaxter, Hughes and Tight, 1996). The reason for which, in terms of the focus group activity, was that given the practical problems of getting a group of busy care workers together at any one time, and to avoid disruption to the daily running of the care home the research team recognised that they needed to be flexible about who took part, and so care workers essentially chose themselves. The strategy worked in as much as all three groups were well attended - possibly because care workers had a rare chance to sit and reflect on care practices- thus recruitment problems, which commonly blight the focus group method, were fortunately not experienced in this study (Morgan, 1995). Except for the senior carer at Encombe who came in especially to take part in the focus group, attendees were all care workers on duty at that time.

### **5.3.4 Sample group 4 – professional staff**

The fourth sample source for this study was people with professional experience of residential care for older people with dementia. A total of 5 participants made up this last sample group; each one purposively selected on the basis that they could shed a particular light on current concerns and priorities in this area of long-term care provision. Given the study's commitment to understanding exclusionary processes from as many different perspective as possible four of the participants in this sample group were home care managers from study sites 1, 2, 3 and 4 respectively<sup>21</sup>. The fifth participant was an Environmental Health Officer who had recently visited study site 3 and so, given the short timeframe of a PhD, 'convenience sampling' was used, as a method of selection for sample group 4 (Blaxter, Hughes and Tight, 1996). I had also hoped to include a professional member of staff from social services (such as an inspection officer) in this sample group.

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<sup>20</sup> In some instances the same care worker took part in a focus group *and* case study.

<sup>21</sup> A representative from the fifth study site, Purbeck Lodge, was not asked to participate in this stage because the managerial staff had changed since the researcher had last visited the Home, and so neither the study nor the researcher were known to key members of the new team.

Unfortunately, despite writing to a number of local authorities, I was unable to access anybody from social services in the short amount of time that there was left for fieldwork at this stage.

Participants who made up the fourth sample source were, of course very different people from a range of professional backgrounds. Figure 3 outlines the general characteristics of this sample group. Apart from Mr. Young who was aged 26 years, participants from sample group 4 were all aged between 40 and 55 years. Mr. Young also differed from the other participants because his primary role was not a managerial but one of an inspector; thus, unlike the rest of this sample group, he was neither physically based in a residential home nor charged with full-time responsibilities to this particular client group or area of residential care.



<b>Participant*</b>	<b>Occupation</b>	<b>Time in post</b>	<b>Background /qualifications</b>
Mrs. Upson	Manger of Encombe House	8 years	RGN
Mr. Vass	Manger of Lulworth Court	6 months	Social worker
Mrs. Downes	Manger/proprietor of Durlston Court	15 years	RGN
Mrs. Williams.	Manager of Nursing Home (inc. the East Wing)	2 years	RGN and psychology degree
Mr. Yates	Environmental Health Officer	5 years	Environmental science degree

**Figure 3** General characteristics of sample group 4

Moreover, he was a relatively recent graduate rather than someone who had previously spent time working in another area of social or health care. The three women in this sample group all had a nursing background; the proprietor of Study site 3 had recently studied for a diploma in geratology, and the manager of the Nursing Home had also studied psychology at graduate level.

## PART THREE

### STUDY FINDINGS

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This part of the thesis presents and explains findings in relation to the research questions identified in section 4.3 of this thesis. The underlying theme of this section is meanings and experiences of social exclusion and inclusion to older adults with dementia in care homes. In particular, the section endeavours to understand and explore what shapes meanings of exclusion and inclusion for the individuals with dementia involved in this study.

The section explains how a combination of societal, organisational and individual factors determined, and equally importantly, limited participants'<sup>22</sup> shaped meanings of exclusion and inclusion. It is argued that participants were excluded not only from certain people and places but also, and more critically, from social identities (such as worker and citizen), which it is argued, are more socially valued than 'old', 'disabled' and being a 'resident' in a care home. In other words, the study uncovered a hitherto unrecognised dimension of social exclusion, that of the marginalisation of social identities. In addition though, what the study also found was that by effecting different modes of resistance, participants were able to offset these influences on social exclusion to varying degrees, and thereby maintain and develop for themselves a personal sense of identity and inclusion.

Given the complexity of this argument it is made in four key stages; each stage is conveyed in one chapter, and so the section has four chapters. The first chapter in this section, Chapter 6 explores how social and economic conditions shaped meanings of exclusion and inclusion to participants'. Chapters 7 and 8 examine how the organisational context of the each of the care homes shaped meanings of exclusion and inclusion. Chapter 9 examines the influence of ill health and normal biological processes of ageing on meanings. Finally, Chapter 10 explores the range of strategies used by individual to resist exclusionary processes.

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<sup>22</sup> Throughout this section, unless otherwise indicated, participants refer to those individuals from the first sample group – that is, older people with dementia living in care homes.

## **CHAPTER SIX**

### **The impact of economic and social conditions.**

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#### **6.1 Introduction**

This chapter addresses the first of the subsidiary research questions about the way social, economic and legal conditions shape meanings of exclusion and inclusion.

The chapter begins the assessment of the social model of disability to understanding meanings of social exclusion and inclusion in this context by exploring how economic, legal and social conditions, in relation to residential care services, impact on participants' rights and responsibilities as citizens.

Discussion begins by exploring the flow of economic and human resources in care homes. This discussion focuses on how long term care is funded and explores whether current levels and systems of funding are adequate to provide the level of staff and training required to promote the social inclusion of older people with dementia. This leads to a discussion about the form of citizenship participation possible in this context. Two issues are examined: the homogenisation of people and families, and the reluctance of residents to complain.

The chapter draws on data collected from each of the four sample groups so as to allow for a comprehensive discussion of all the issues that can potentially shape meanings of social exclusion to an older adult with dementia living in this environment. It is argued that meanings of social exclusion and inclusion change, as a result of a person moving into a care home.

#### **6.2 The care home industry**

In Britain, the independent sector, local authorities and the NHS, share the provision of long-term care of people with dementia (Schneider, et al. 2002). Because of major changes to the commissioning strategies of health and social care services during the 1990's (Laing,

1997), the independent sector is now the largest single provider of long term care for older people providing a total of 165, 236 residential places to people aged 65 years and over, and 17, 229 specialist residential places to 'older mentally infirm people' (Department of Health 2001a). The main driving force behind the steady development of the care home industry in Britain over the past three decades has been the ageing population (Laing, 1997).

New legislation has influenced the supply and demand for this service: the demand for a care home place dropped with the passing of the Community Care Act (1990) (Laing, 1997) and the number of residential and nursing homes for older people decreased with the passing of the Care Standards Act (2000) (DoH, 2001a). Taking into account market fluctuations and other variables (such as changes in the caring capacity of individuals and communities and developments in health technologies) Wittenberg et al. (1998: 46) calculate that the care home industry would need to expand by around 61% between 1995 and 2031 to keep pace with the ageing population. Literature pertaining to the desirability of this form of service provision for an older person with dementia was discussed in section 2.4 of this thesis. This section concentrates on how the growth of the care home industry shapes meanings of exclusion and inclusion for the individuals who live in a care home.

The financial cost for both the individual and those responsible for publically funded care is probably the single strongest influence shaping meanings of exclusion and inclusion (Netten, et al. 2001). This is because, despite the recommendation made by the Royal Commission on Long Term Care that all personal care – nursing and social care – should be free, the social care that people receive in a care home in England and Wales has to be paid for either by the individual or social services.<sup>23</sup> Analysis of the information brochures produced by the care homes involved in this study for prospective service users revealed an

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<sup>23</sup> This decision and the three tier financial banding that goes with it only affects older people in nursing homes, as people in residential care homes with nursing needs have these met by NHS through a visiting district or community nurse (Alzheimer's Society, 2001). Scotland responded differently to the recommendation made by the Royal Commission on Long Term Care and made all personal care – nursing and social care – free at the point of need.

absence of factual information about the cost of the service to the individual: Durlston Court and the East Wing – the nursing home- did not mention cost at all. The three Carstairs Trust homes, which did directly address the issue of cost in its brochure, did so, so as to reduce any anxieties that a person might have, it read:

***‘Concerned about the cost?’***

don’t be put off if you are concerned about the cost, or about losing any benefits you currently receive. Financial help is often available from local authorities and we will be happy to help you obtaining any benefits you are entitled to’

(Information leaflet, Lulworth Court).

This organisation portrayed the issue of cost as a purely financial one, recognising that many older people do not claim the benefits they are entitled to (Tinker, 1997a). There is a depth of knowledge relating to poverty and older people (Townsend, 1979; Walker, 1993; Scarf et al. 2000); however, very little is known about how an older person who uses and needs this service *feels* about paying for their long term care, and in particular, whether or not they consider they are getting value for money. In this next extract, despite knowing that social services would step in and pay for her upkeep, as and when her financial resources dried up, Mrs. Wells still worried about having to support herself for an unknown period of time on a limited and diminishing income:

Well, I worry, and (my daughter) says there's no need for me to worry, you see, things like that, so I say, 'well I can only stay here as long as my money lasts' (laughing). There's one lady this week who's 104, so I said, 'it's no use me living until 104, I couldn't afford to!'. Actually, I know Social Services stepped in, but I don't want Social Services

(Mrs. Wells, age 97, Lulworth Court).

Mrs. Wells was concerned about the cost of living, quite literally. She was also worried about having to become a recipient of social service benefits, perhaps resisting the ‘benefit-induced female dependency’ said to characterise strong ‘male-breadwinner states’ (Lister, 1997: 173).

Blackman (2003: 156) notes how the 'major cause of dependency for older people as a group is low income arising from compulsory retirement'. However, this view overlooks other sources of income available to older people besides employment. Tinker (1997a) notes that the majority of older people in all age groups are owner-occupiers, a social fact that was remarked upon by one of the managers involved in this study:

It is not only people from the middle class – if I can use the class system that have money now. People have got property now, especially in the (southeast) and had it for a long time, and the value of it has increased tremendously.

(Manager of Encombe House)

This participant seemed to recognise the importance of property in generating income for all social class groups. However, for an older person in need of long term care, this privilege often has to be relinquished, as anyone who has assets above a certain level (currently £16,000) are not entitled to public support in paying for residential care (Netten et al. 2001). In other words, an individual (or their representative) has to prove eligibility for what is a means-tested benefit. A process which is in itself exclusionary (Twine, 1994). Mrs. Phelps, age 68 years of Encombe House, described what effect exclusion on these grounds had on her. She said, 'I worry about whether I will have enough money to live on for the rest of my life. I live on a state pension. I had to sell my house to pay for my upkeep here'. Like the majority of woman her age, Mrs. Phelps had no pension of her own to rely on, only the state pension (Burden, 2000). Moreover, she paid for her upkeep from the proceeds of the sale of her own home (Royal Commission on Long Term Care, 1999). Another participant described the sense of exclusion a loss of income and property rights can evoke:

It's a nice little place but I would rather have a home of my own. Because I shall never have one now I don't think because they take all the money. Yes, going back to my own home, but isn't mine now, you see it is sold. A little house by myself... They are very nice like that, they are kind, but....I want a home of my own

(Mrs. Wright, age 83, Lulworth Court).

Selling her property to fund her care ruled out the possibility of her ever owning her own home again. A loss that seemed to be for her more of a metaphysical one than a physical or financial one, as 'the private house can in some ways be seen as symbolizing the private self; it is a container with clear boundaries which shut out the public world' (Billington, Hockey and Strawbridge, 1998). It would seem that homeowners are particularly vulnerable to economic pressures (Wright, 2000).

Moving into a care home obviously means different things to different people (Higgins, 1989; Gurney and Means, 1993). Thus, the growth of the care home industry impacts differently on individuals who need long term care. For example, Mr. Spinks felt that he and his wife were privileged because they could afford a place; here he describes the events leading up to them moving in:

And (our social worker) said Encombe House had just been opened and they were looking for people who had the money to pay. If you didn't pay you couldn't get in then. So we had savings put by and so we got in you see. Well once your money has gone then they take over and Social Services pay for you. But it is £400 a week you see so it is a lot of money

(Mr Spinks, age 90 years, Encombe House).

As far as this participant was concerned, living in a care home was a sign of prosperity rather than poverty. This view of care home life might be counterintuitive for many people. It was noted in section of this thesis that a large-scale survey of public attitudes to social exclusion across Europe found that 'living in a home for the elderly' was ranked as one of the signs of poverty (Golding, 1995: 218). The same attitude was also reflected to a certain extent in this study. For instance, when Mrs. Wells of Lulworth Court described her daughter's reaction to her decision about moving into the home. She said, '(my daughter) said, "they say it's a place where they take anybody", so I said well, "I am anybody, I've worked on District Health all my life, what else am I?" And Mr. Brown, one of the case study participants, after I told him that I would be visiting a gentleman who lived in a

sheltered housing scheme later that day, he said: 'I bet he has got a bob or two more than what we have got'.

Rising incomes of older people lead to rising inequalities in their income (Wittenberg, et al. 1998). Indeed, as Mr. Brown quite rightly implied, tenants in a sheltered housing scheme do generally have more disposable income than their counterparts who live in residential care (Joseph Rowntree Foundation, 2000). Given the lack of information available about the effects of quality of care (Netten et al. 2001) one might suggest that Mr. Brown's sense of deprivation could have been an effect of poor care rather than income, as elsewhere he commented on how exclusionary care practices felt to him. He said, '(care staff) don't seem to want to talk to you anyhow, or something like that - once they have got their money they are happy'. Mr. Brown sounded negative about his experiences of being a consumer of this type of service, perhaps because he felt that standards in the home could and should be better.

Efforts to promote the social inclusion of older people in care home through the raising of standards were discussed in section 2.4 of this thesis. That discussion highlighted how negative public attitudes can be towards care homes for older people. Public perceptions of what a neighborhood is like can be an influential factor in the polarisation of that area (O'Connor & Lewis, 1999; Reay & Lucey, 2000). Managers involved in this study offered their opinion as to what shapes meanings of exclusion in this respect:

I suppose family's perception very often, particularly the younger members of a family might be put off by visiting an old folks home, they might find that a very depressing experience and so I would say that may be time those visits might diminish.

*And you see that happening do you?*

Because I don't work at the weekend – I am on call – it is traditionally the time when people have more time to visit, I can't comment with any degree of certainty. However I have noticed that the grandchild who you expect in the twenties or thirties you don't see much of that.



*And you think that that is to do with the association of people being in a nursing home?*

Yes. They don't like the environment and being surrounded by older people.

(Manager of the East Wing)<sup>24</sup>

This manager had concerns about the social exclusion which could be triggered by someone being in this form of housing; a concern partly borne out by a recent large scale health survey of older people in England which found that 81 per cent of those living in private households were visited by friends or relatives at least once a week compared with only 64 per cent of older people in care homes (DoH, 2000). Another manager describes how meanings of exclusion are fuelled by misperceptions about the type of person who lives in a care home:

The general perception of people living in an old people's home is of people who sit there waiting for God and they are sitting there dribbling and making no sense whatsoever and that is the perception people have and that is the perception of people who have been in here, they see it very much in the role of workhouse because that is the institution – may be the only institution they have ever known about or you know read about or whatever and it is getting rid of that myth

(Manager, Lulworth Court).

This manager clearly believed that the heritage of this form of housing led others to think that the type of person living in it was someone who was 'mad', dependent and disappearing, and that part of his role was to try and debunk that. Clearly, the experiences of this participant had led him to suppose that the exclusionary view of care homes as 'symbolis(ing) dependence, an inability to control one's own affairs and a reliance on others' is common to many people (Allen and Crow, 2001: 191).<sup>25</sup>

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<sup>24</sup> In this and all subsequent quotes, the words of the interviewer are in italics.

<sup>25</sup> The issue of independence is discussed in section 7.4.1 of this thesis.

The heritage of a building certainly seems to dominate peoples' perceptions of the people living in it (Bond, 1993). The dominance of negative perceptions concerning residential care were further evidenced in this study by some of the assumptions underlying text in the information leaflets produced by study sites. For example, the final sentence in the Durlston Court information leaflet, which was in larger font than other text and in bold typeface so as to emphasise its importance, read, 'we aim to stimulate rather than leave residents to 'sit'. This suggested to me an assumption about both the audience of the leaflet – that is, relatives of prospective of service users rather than service users themselves, and, that the reader would be concerned about people being bored and left to disengage; a perception that was discussed in section 1.2 of this thesis. By contrast, underlying the information leaflet produced by the East Wing seemed to be the assumption that care homes exclude families, as it stated, '(r)elatives are not forgotten'. Again, there is evidence to support the validity of the assumption that relatives of older people with dementia are often excluded partners in dementia care (Hertzberg and Ekman, 2000). The assumption is highlighted here to evidence the extent to which service providers seem to take for granted the prevalence of the negativity that surrounds residential care services.

Finally, the growth in this form of service provision has given rise to other influences shaping meanings of exclusion and inclusion. For example, the Audit Commission (2002) found that the amount and location of continuing care provision for older people with mental health needs varies considerably across England and Wales; only two thirds of areas surveyed for this report had specialist residential care provision for older people with mental health problems<sup>26</sup>. Woods (1995) also suggests that financial limitations and registration requirements in the UK restrict more inclusive approaches to providing long term help and support for this group of people (the author gives the example of the staff intensive domus type developments popular in France and Sweden). Funding arrangements for residential care by the public sector also tend to be inflexible and pricing strategies are often low and non-negotiable (Forder, Kendall and Knapp, 2000). One of the managers involved in this study, described the implications of this on her admissions policy:

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<sup>26</sup> A consequence of this is discussed in section 7.2. of this thesis.

The funding that we get for residents just isn't enough. And I really had to go private because at the moment we are still in partnership with the Local Authority but they are withdrawing that and the only way I can keep going is if we have enough people paying the full cost'

(Manager, Encombe House).

As far as this manager seemed to be concerned the subsidized rate that social services paid for a person's care was not enough. However, unless and until more is known about the effects of quality of care, costs will continue to be related to the type of home rather to the severity of cognitive impairment (Netten, et al. 2001: 21). All of these factors lead to strained relationship between local authorities and service providers (Wright, 2000). A strain that arguably does not help the position of older people with dementia, and other older people living in care homes.

### **6.3 Staffing residential care services**

For reasons outlined in section 2.4 of this thesis, historically, care homes for older people have been seen as undesirable places to work: pay is usually low and the physical and emotional demands made on an employee by this type of care work are often undervalued (Garner, 1998). Due to the even greater demands of caring for someone with psychological and behavioural symptoms related to dementia, specialist residential care services (for older people with dementia) are even more likely to be seen as the 'cinderella service' of health and social care provision (Kitwood, 1993). The poor status and image of the care and support sector generally, is a serious problem which Government is urged to address (Henwood, 2001).

Recent quality initiatives recognise that operational staff are key players in the promotion of inclusive services for older people (Little, 2002). As the manager of Lulworth Court in this study said, it is about 'realising that people who actually work with older people are no longer the Cinderella service of the social services, that they play a very important role'. The importance of valuing and supporting staff through proper pay, support and recognition of their services is frequently noted in the dementia care literature (Kitwood,

1993; Cantley, 2001). Moreover, New National Minimum Standards exist to ensure minimum staffing ratios in care homes for older people are achieved, and adequate support and supervision is provided to care staff (DoH, 2000). However, the Alzheimer's Society (2000a) seriously question whether the current set of staff-related standards are sufficient to promote the social inclusion of people with dementia. Furthermore, a recent inquiry into the quality of support to people who needed help due to frailty in old age, mental health problems or other health related needs found that the care sector is chronically under-funded and under-staffed (Henwood, 2001). This section is grounded in this debate and informs it by explaining how the staffing of care homes in this study influenced the status and opportunities of a small group of older people who were cognitively impaired.

Employment trends and conditions impact on the recruitment of staff to residential care homes. These trends are discernable at many levels. For example, the current international trend, and politically controversial one of recruiting nurses from developing countries to work in the West (Royal College of Nursing, 2000) was how the East Wing staffed its service. However, it was local trends that the care home managers who took part in this study spoke most readily about. For instance, the manager of Encombe House described her frustration about not being able to recruit staff due to *competition from local* employers:

I think because we are in a very high employment area. We don't pay massive salaries and it is a demanding job. You know we have got 41+ staff to look after every day and make sure they are happy and I think because of the outlets around here we have got lots of retail outlets now and also we have had a new shopping mall built nearby with hundreds of food outlets there – well not hundreds but many food outlets and I have spoken to health professionals, I have spoken to social services agencies. I have even spoken to the employment people and they all tell me it is because the only people left at the moment are people who don't really want to work. And traditionally I mean for catering assistants your pay is – well I think it is not bad here – but it is not terribly good so it doesn't attract people

(Manager, Encombe House).

The manager of this home clearly found the recruitment and retention of all staff groups quite a challenge in the current economic climate of high employment (and house prices) in the southeast. One of the consequences of this, in this home at least, is an over reliance on agency staff, which, from what the manager says, seems to be unsatisfactory as far as all are concerned:

(Residents) don't complain so much about the kitchen as they do about care agency care staff. They say they don't like it and I say neither do I but we have the same problem there.

*So what sort of complaints do they make about agency care staff.*

Well because they feel they don't – they like to know the staff and although we have regular agency care some of them haven't got a key worker and they are missing out on what they see everyone else having.

(Manager, Encombe House)

Continuity of staff is known to be a desirable factor in the well being of older people with dementia in care homes (Cantley, 2001). Given the remarks made by this manager, regional variations, and market forces are likely to exist which influence the achievability of this outcome.

To overcome recruitment problems and to increase job satisfaction amongst staff, employers in the care industry are advised to provide flexible working arrangements and to offer employees adequate protection and support (Royal College of Nursing, 2002). This was the approach taken by the manager of Durlston Court in her attempts to staff the home; even so, as she explains, she still had difficulties with recruitment:

We fit all (staff) in to a rosta according to what they can do, whether it is some people do nights, some people just do days, some people just work in the day, some people just work in the evening. Some people work full time in which case they will do three 8-5s, two 5 to 10s which make up the 37 hours and alternate weekends, but there are not many of those now. It is hard to find staff

(Manager of Durlston Court).

One of the consequences of a lack of staff is that the social rights of citizenship such as mixing with the local community (Centre for Policy on Ageing, 1984) and opportunities for self development (Twine, 1994) are more difficult to make happen, particularly for people who are cognitively impaired. For example, as the manager of Durlston Court explains, it makes it difficult to organise social events inside the home:

‘we like plenty of activities and people to join in but again it is down to the staffing levels. We have never had a problem before but we are seven down just lately and we have a problem (Manager, Durlston Court).

Despite her positive intentions, people living in the home were at risk of ‘missing out’ of because of staff shortages. Similarly, the manager of Lulworth Court described how difficult it was for his home to always meet a person’s request to go into town:

If Mrs. Clarke comes up and says that she wants to go into town then if we have the resources we will do it.

*The resources being?*

The resources being staff, because I am not going to sit here and say then we will go into town, because that is not realistic. Sometimes we just can't. There are other times that we can, most times we can and often she will go into town with one or two of the residents and just a key worker.

(Manager of Lulworth Court, talking about Mrs. Clarke).

In these two instances, a lack of staff seemed to be the only barrier to this aspect of peoples’ social rights to citizenship being fulfilled. However, social exclusion theory reminds us that there is often a range of factors combining to produce exclusionary processes in any given context (Percy-Smith, 2000).

Elsewhere, the manager of Durlston Court explained how a lack of staff was just one of many factors preventing peoples’ access to the local community:

We are away from the main village which means that (residents) can't go out alone – and we do have quite a busy road now, which wasn't when we started, so they can't just potter to the shops, though the people I have here might be difficult in a shop, they might have difficulty, or the shopkeepers might ask us for them not to go. We have people who would not be able to go, but given a carer with them they could go. We still would like to do that, we do that occasionally but it is having enough staff. Because we have got to have staff here and we have got to have enough to go out with people. Which can be a bit of a problem. We could do with more help with the staff really, volunteers and thing

(Manager of Durlston Court)

The particularities of the place – the 'busy road' and rural location - societal attitudes about mental health problems, levels of disability and frailty, and chronic lack of staff combined to make a person's right to citizenship in the form of 'mixing with the local community' (Peace, Kellaher and Willcocks, 1997) a very difficult one to fulfil in practice. The compounding processes of exclusion are clearly at play in this instance (MIND, 1999).

The staffing of residential care homes is not simply about the quantity of staff but also the quality of care practices they deliver (Tune and Bowie, 2000). From this perspective it is possible to discern how by making the concept of citizenship more meaningful for this group of people in this situation exclusionary processes can be reversed. Here, the manager of Durlston Court described her attempts at bringing the outside world into the home given the problems she had getting people out:

We have a newsletter here. We try to do it fairly often telling people what's going on, but that is for staff and residents and for visitors. So we tell them when the council next meets and who is coming, because we have found that families have said to us, I would have come if I had known. So we try to do that. And we had a poem made up by the residents in the poetry class or things like that or relatives send poems, so we have things like that to kind of improve things. And we do have – we have got people coming in from the community sing to us and play to us at Christmas and we do have children from the local school.

(Manager of Durlston Court)

The regular production of a newsletter in this home seemed to enhance relations between not only the local community and the home but also relatives and care staff. The value of involving relatives more in the membership of a care home is noted in the literature (Hertzberg and Ekman, 2000). In the context of this study, it is possible to see how an activity like this has the potential to extend the meaning of citizenship to an individual participating in *any* shared and communal activity, not necessarily one that is orchestrated by the state (such as voting) (Faulkes, 2000).

#### **6.4 The homogenisation of individuals and families.**

Modern concepts of citizenship are defined primarily as a set of individual rights - 'rights give space to the individual to develop their interests and fulfill their potential free from interference from other individuals or from the community' (Faulkes, 2000: 56). The homogenisation of people is a problem as it disavows this principle. Not only that but it is mistaken to think that simply because a group of people are of the same age or have the same condition, then they are necessarily the same 'type' of person facing (or creating) the same problems and pleasures. In this section it is argued that the service and regulatory framework, which underpins residential care services for older people with dementia, shapes meanings of exclusion and inclusion by propelling the tendency to treat people as part of a homogenous group, rather than as individual citizens.

The tendency to homogenise older people, and older people with dementia, is partly evidenced by other studies, which explore the direct impact of regulation arrangements on people living in this type of environment (Willcocks, Peace and Kellaheer, 1987; Peace, Kellaheer and Willcocks, 1997; Peace and Holland, 2001). And partly evidenced by the discussion that follows, which draws on and contributes to this debate by focusing on the *indirect* impact that these arrangements have on people through an analysis of the working practices and attitudes of service providers and inspectors who took part in this study. During the life of this study the Care Standards Act (2000) was passed. This single piece of legislation sets out for the first time a national system for regulating social care (Henwood, 2001). Part of that system involves the inspection of care homes by representatives of the National Care Standards Commission. Up until then, local social services departments



inspected care homes and it was they who had written the inspection reports analysed for this study. In the next two extracts, it is possible to see how easily the individual rights and service standards that one might normally expect in a residential care home (such as access to information and privacy when making a phone call) are dispensed with when older people with dementia in care homes are treated as a homogenous group:

‘as the home specialises in the care and treatment of people with dementia, copies of the Brochure are given to residents’ advocates rather than residents themselves....

...the residents phone is in the corridor. This seems appropriate given the category of resident accommodated’

(Inspection Report, Durlston Court).

Having categorised people according to ‘the type of resident accommodated’ – that is, according to dementia, everybody living in Durlston Court was seen and treated as a member of this particular client group rather than as a citizen with an equal right to information and services. Consequently, opportunities for a person to retain or relay written or verbal information were reduced, as was the chance of being seen as an active family member who might need or prefer to have their own phone to keep in touch with people. While the education needs of both formal and informal care workers are well recognised by researchers (Askham, 1997; Fellows, 2000; Killeen, 2001; Bryan, et al. 2002) the training needs of inspectors are not.

The model of partnership working described by Clarke (1999) whereby professionals work together to share knowledge is arguably one way of meeting the information needs of inspectors and of reducing the indirect impact of disabling attitudes on peoples’ level of rights. The Environmental Health Officer who took part in this study claimed to approach the health and safety inspections that he carried out ‘from a holistic point of view’. However, in the extracts that follow, the Officer clearly did not mean ‘holistic’ in the spiritual dementia-care sense (Braudy Harris and Durkin, 2002) as he too had a tendency to homogenise people:

I mean when the Human Rights Legislation came in you know we have obviously taken that into account. We do inspections and when you interview people and you think about what human rights have those people got in there. But on the other hand when you have got people who have got I don't know, learning difficulties, don't quite know what is going on around them, with dementia and so on.

A lot of the people in retirement homes have got dementia problems and therefore what information would I get from talking to them and so I can just look at them

(Environmental Health Officer).

Because the Officer took for granted the effects of dementia (and learning disabilities) he assumed no one would be able to speak with him. Instead he saw and treated everybody as voiceless objects to 'look at' without any human attributes other than 'dementia problems'. Clearly there *is* a need develop dementia care partnerships (Clarke, 1999).

Theoretical developments in dementia studies emphasise the importance of breaking down the 'them' and 'us' mindset in care delivery – 'them' being the cognitively disabled and 'us' being the cognitively able (Kitwood, 1993; Kitwood and Bredin; Kitwood and Benson, 1995). Data collected from this study highlighted how deeply embedded this homogeneous way of thinking is in social care culture. The acceptability of thinking about people in residential care as, in this case, two distinct groups according to their mental health status, was clearly evidenced when the senior care worker described how she organised people when it came to planning a day trip:

Ms. B                      It depends where I am going but if there are no objections. Usually what I try and do is divide the group up so that the demented ones go together and the ordinary ones go together, because some of the ordinary ones are not that tolerable of the demented ones.

(Care worker – Encombe House)

So, whilst everybody got the opportunity to go out for the day, not everybody got the chance to be considered 'ordinary', as this care worker's use of the term 'demented' served to differentiate between those who were 'normal' and those who were not. From a disability perspective, the concept of normality is a problematic one, as the 'boundaries between what is disabled and non-disabled and healthy and ill are not as clear cut' as this concept would suggest (Marks, 1999a: 80)

Openness to the idea of 'other-ness' is said to bring about social inclusion for people with dementia (Barnett, 2000). This basically involves those who are not cognitively impaired treating people who are cognitively impaired as equals. In the following excerpt from a focus group discussion, someone with dementia was referred to as an equal rather than as someone 'other' and that caused amusement:

Mrs. M            I don't know really because I know it sounds silly but I seem to blend in very well with (people with dementia).

All                (laughter)

Mrs. M            I don't know I have always seemed to - its weird but be on a sort of same wavelength. I know that sounds silly. But I always talk to them, I hope, as another human being on the same sort of level in a way.

(Care workers – Durlston Court)

The laughter that Mrs. M provoked when talking about being able to relate well to people with dementia, suggested that there was something amusing about this type of attitude. Mrs. M recognised this when she said how she knew it sounded 'silly' but nevertheless, saw no reason why she should not consider a person with dementia 'on the same sort of level' to her, as an equal rather than as someone inherently different or shameful in some way. By speaking of people with dementia in this way this care worker revealed how the act of caring, in itself, need not be oppressive, only the judgemental basis which underpins it (Swain and French, 98).

A similar process whereby a non-stigmatised person (like a care worker) was able to 'break through' and to see a stigmatised person (a person with dementia) as a real, whole person with a variety of attributes and identities (Coleman, 1997: 222) was also evidenced by a story told by Mr and Mrs Spink. In this case another resident (probably with dementia) was seen as someone with a sexual identity whom Mrs Clarke at least, could have a 'laugh with'; her husband's contributions to the story served to remind the interviewer that the person whom she was referring to *was*, in his view, 'abnormal':

*Mrs. Spink* We were sitting in the hall waiting for this happy shopper man to come once and he yelled out - how is your love life? I said pardon.

*Mr. Spink* He is as nutty as a fruitcake, oh he really is.

*Mrs. Spink* I said he said how's your love life. So I said well we are on nil these days so he said yes but it gets a bit boring here sometimes doesn't it. I thought that was so funny.

*Mr. Spink* When he first came in he was talking quite normally and I thought here's is one who isn't nutty. Anyway we went up in the lift one day and I pressed the button once and he said I live on the fourth floor you know. Well there is no fourth floor. Then he realised it.

(Mr and Mrs Spink, age 90 and 91 years, Encombe House)

Whereas Mr Spink had clearly decided that this man was 'mad' and hence different from him and his wife, Mrs Spink had seen him, albeit fleetingly perhaps, as an equal, as someone with an identity other than 'mad'.

The 'folly of generalising' when talking about older people is noted in the literature. As Tinker (1997a: 7) points out, social class, family support, physical and mental disability vary amongst older people as much as they do amongst the rest of the population. The language of rights that pervades long-term care literature and policy is designed to counter this tendency (DoH, 1989; 2001; Smith, 1997). However, what is less well researched is how, in practice, those who provide and inspect services respect these rights and see people as individual citizens rather than as a member of a client group.

According to Hyde (2000) the consequence of a homogeneous approach to people with impairment is that it groups people in terms of 'the disabled' and then systematically discriminates against that group. The information brochure produced by the East Wing I think evidences this, as it stated that 'the home provides safe, comfortable and secure care for *the elderly mentally ill*' (my emphasis). The problem with this phrase is that by describing the home as a place for 'the Elderly Mentally Dependent' diversity and difference amongst those living there is denied and negative assumptions about them are at the same time projected (Fawcett, 2000). The centrality of the social category of 'demented' in the lives of people with cognitive impairment becomes clear then, as regardless of a person's gender, ethnicity, profession, social class or educational background it is likely to be mental health status –dementia - which determines how others see and treat them. In effect, dementia becomes the 'master status' to which most other identities are subordinate (Becker, 1963: 32, quoted in Jenkins, 1996: 156).

The importance of maintaining contact with family and friends, particularly for someone with dementia is noted in the literature, 'stable and caring relationships can provide comfort, security, and feelings of inclusion that are threatened by the disease' (Synder, 2002: 113). A potential problem with this view is that it can homogenise the families and carers of people with dementia. For example, this manager saw relatives as behaving in one of two ways:

What I find with residents with the dementia with regard to relatives and staff is you get one of two things, you get relatives who will be in complete denial, why is she doing that, she never used to do that, she has gone down hill since she has been here and so they are in total denial and waiting for someone to blame and that is usually us and so we will talk through with the relative and they are fully aware of their mother's condition, if any one sat down with them and explained what a dementia is and they say yes but that is not what mum has got or because again people will keep control and relatives will remember the peaks and say well she has never done that, she always used to be such a tidy lady, we have this sort of thing. Or you get the other relative who is very well informed and very understanding and can cope with it and will respond to it in a much more positive healthy way. And so we have the two sides of the coin. Which is fine because we have relatives who may have more knowledge than the staff and can impart that knowledge to them

which is always useful and always encouraged. And as I say then you get the ones that are into total denial either through ignorance or through self-preservation.

(Manager of Lulworth Court)

This manager felt that family members responded to a relative with dementia in one of two ways, either to protect their self, or to protect their relative with dementia. Research suggests that not only are the perceptions of carers of dementia more diverse than this (Askham, 1995) but more fundamentally, the characteristics and experiences of each family are different (Allen and Crow, 2001).

According to Finch (1996) health and social care policy is largely based on the assumption that family members will automatically be willing, able and sufficiently informed to assume responsibility for each other. The large body of work in dementia studies on the support and educational needs of carers suggests that too often this is not the case (Nolan and Keady, 2001). One of the reasons why Finch (1996) has a problem with the current emphasis in policy and practice literature on professionals working more closely with family carers (DoH, 1999) is because in her large-scale survey of families she found a 'lack of agreement about norms of family responsibility'. Nevertheless, she says, professionals all too often assume that a family member will and should take responsibility in decisions about a family members care. This certainly seemed to be how one of the managers involved in this study saw the role of family members:

*Is there an opportunity for potential residents and their families to come and visit?*

We encourage all of that.

*And do they normally take that up?*

Yes. In fact I won't offer a place unless there is family there – I won't offer them a place until (the family) come and look around. I won't do an assessment, and I say you actually have to come and look yourself and make a conscious choice and then make a decision.

(Manager of the East Wing).

It seemed to be this manager's opinion that family members should be involved in the admission process, and because dementia care studies has so far analysed familial relations using a partnership model there is a clear body of evidence supporting this approach (DoH, 1999; Nolan and Keady, 2001; Davies, 2002). However, if one were to use the concept of citizenship to understand the meaning of the role of families to people with dementia, then a different perspective might emerge.

Avoiding becoming a burden on their children is cited in the literature as one reason for why an older person moves into a care home (Wilson, 2000). Allen (2002) reflects on work carried out by herself and colleagues over the past decade and concludes that for many older people the move into residential care is a positive one and preferable to living in increasingly difficult circumstances. Oldman and Quilgars (1999: 376) suggest that rather than viewing this negatively, as 'evidence of peoples' concerns that they had become a burden on their families and on society', one might see it as a positive decision on the part of the older person. Here, Mr. Smith describes how he had considered moving in with one of his sons but decided in the end to move into the home:

I don't know. You see like I keep telling you, they are all at work now, you see, so they couldn't take me in. They would have done if one of them was at home. But there you are these days the wife and all work. They have all got important jobs you know.

*So, (moving in with your son) is something that was considered was it at the time.*

Yes.

*The possibility of your staying with either of your sons.*

Yes. But any way I feel I nuisance. I would do. I would rather stay here. Where people have got the time to look after you I suppose.

(Mr. Smith, age 83, Encombe House)

In Mr. Smith's view, wider material realities (such as his son and daughter in law having to work) meant that it would be impractical for him to live with them, particularly as he required considerable help and support. Arguably, moving into a care home provided Mr. Brown with what Finch (1996: 206) considers being, the basic social right *not* to have to rely on one's family.

## **6.5 Propensity to complain**

The act of complaining is seen by Government to be an important demonstration of citizenship (Prior, Stewart and Walsh, 1995). The Citizen's Charter and more recent public service developments, which shore up complaints procedures, to support service users in their endeavours to speak out against the services they receive, are clear indications of this (Tinker, 1997). As Manthorpe (2001:189) points out, 'the language of patients' rights has provided some counterbalance to notions that medical experts know best'. Despite these positive policy initiatives researchers often find that older people generally do not generally complain about the services they receive (Allen, Hogg and Peace, 1992; Peace, Kellaher and Willcocks, 1997; Nystrom and Segesten, 1994). Even more worryingly, it is suggested that people with dementia in institutions are unlikely to complain or be heard if and when they do (Brooker, 1995; Marshall, 2001). This section draws on this area of research and contributes to it by showing the diversity amongst older people in terms of propensity to complain.

Oldman and Quilgars (1999: 378) argue that with 'marketisation comes the expectation that older people will behave like consumers'. As already implied, part of the role of a consumer is to complain (Prior, Stewart and Walsh, 1995). This expectation is now placed on older people in care homes, even though, traditionally, people in this situation are not used to being asked their views (Atkinson, 1998). Differences in the propensity to complain were evidenced in this study as several participants offered their opinion as to how, why and when they or others in the home spoke out as consumers. First, Mr. Spink at Encombe House, who seemed to have no hesitation in exercising his rights and



responsibilities as a consumer, as when asked if he attended resident's meetings, he replied:

Not half. But nobody will say a word. You don't get a word out of anybody.

*Why do you think that is?*

I don't know, I don't know. I just don't know. But there is a resident who will complain and he will complain like old Harry, but when it comes to a meeting not a dicky bird, its lovely, its beautiful.

(Mr. Spink, age 90, Encombe House,)

Mr. Spink seemed to find it frustrating that this man would complain to him in private but not to others in public. Peace, Kellaher and Willcocks (1997:68) give a range of possibilities for why an older person in a care home might not wish to complain, including the fear that ingratitude could lead one being asked to move, and the possibility of being bullied, ostracised or victimised by other residents. It would appear that some people in this study were reluctant to complain about the services they received, for these sorts of reasons.

After saying how eagerly he attended residents' meetings, Mr. Spink went on to explain with the help of his wife, why he thought people in the home were reluctant to complain:

*Mr. Spinks*      you have to be very careful who you are complaining to – they will sling you out of here.

*Mrs. Spinks*      You see they can - I understand they can put on you a list whereby you get moved out if you are a nuisance.

*Mr. Spinks*      If you are a nuisance.

*Mrs. Spinks*      If you are on it.

*Interviewer*      There is a list sorry?

*Mrs. Spinks*      They could put you on the transfer list.

*Interviewer* Right. Has that happened then to anyone?

*Mrs. Spinks* I have heard of it.

*Mr. Spinks* We have heard about it but we don't really know, we never know you see

(Mr. and Mrs. Spinks, age 90 and 91, Encombe House).

Mr. and Mrs. Spinks expressed a fear common amongst people in their situation, and that is of being excluded if one were to express ingratitude. So strong, seemingly, was the myth in this care home about a transfer list that it had the ability to construct and conserve a way of being (Shurmer-Smith and Hannam, 1994: 31) – that is, one of not complaining.

Acquiescence has been described as a generational trait: older women in particular are thought to be a group least likely to complain (Nystrom and Segesten, 1994). However, what data from these participants seems to indicate is that not wanting to complain might be due to a fear of exclusion from the care home rather than to a social division like age or gender. This is further evidenced by how Mrs. Phelps responded to a question about what she would do if there something in the home that she did not like:

‘What about this place. I keep my mouth shut. Some things you can say and others you can't.

*How do you know which things you can and cannot say?*

Well you know you can't run the place down - it is just not done.

*So what things can you talk about?*

Not a lot. I told you I wouldn't be much good at this.

(Mrs. Phelps, 69, Encombe House).

Mrs. Phelps was clearly not prepared to say anything negative about conditions in the home; in her view it seemed to be inappropriate to be critical of the home and so was unwilling to talk to me about that, maybe because she feared being ostracised by other

residents or staff within the care home as a result (Peace, Kellaher and Willcocks, 1997). Mrs. Housel also spoke of the general lack of propensity to complain amongst residents in this home; this is how she explained why other residents did not tend to speak out during residents' meetings, 'people are frightened of being disliked I think if they grumble'. Similarly, Mr. Smith remarked on this cultural aspect of the home, he said, 'I haven't heard anybody moan yet', although he might, of course, meant by this remark that there is nothing to complain about. Arguably, the lack of propensity to complain in this care home reduces the 'possibility of participation to make (the) community a better place' (Scott, 1994).

Alternatively, if one were to understand the act of complaining from a 'lifecourse' perspective (Vincent, 1995), which would involve analysing the propensity to complain on the basis of *who* people are rather than where people are, a different picture of community participation might emerge. For example, in the next extract, after telling me about the many losses in her life, including her husband very early on in her marriage and physical health due to a stroke, a participant tells me how complaining would conflict with her sense of identity:

I never complained. When people came to see me I feel they don't come to see me to hear all my moans, and I have got one particular friend when her daughter went off to university and she came in and she said to me you are the person for me to come to see, you will cheer me up

(Mrs. Van Houghton, 79, Encombe House).

This woman's preference to present herself actively as someone who did not complain might be interpreted as a skillful way for her to survive (Ginn, 1993). The same might also be said of Mr. Brown; this is how he responded to a question about how he found living with other people:

Oh I have got no complaints at all about any of it. You could make it awkward if you wanted to.

*You could make it..?*

Difficult for people if you wanted to, some people are awkward to get on with aren't they?

*Yes.*

But I don't worry about that.

(Mr. Brown, 84, East Wing).

Mr. Brown recognised his capacity to create problems but judging by this, and other data pertaining to him, seemed not to. A decision that could be construed as politically astute given that he had already has one experience of relocation. According to Marshall (2001:181) 'people with dementia rarely complain or explain what is going on'. Maybe this is because they decide not to.

## **6.6 Summary**

This chapter has been grounded in the sociological model of citizenship and has explored how economic, social and legal conditions in relation to residential care services for older people with dementia shape meanings of exclusion and inclusion. It has examined the economics of long-term care and the impact this has on both individuals and organisations. This led to a discussion about the problems service providers face trying to recruit and retain staff and the impact of these wider employment trends on an individual's right to participate in the local community.

## CHAPTER SEVEN

### The Organisational Context I: Locality, space, access and values.

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#### 7.1 Introduction

This chapter is the first to address the second research question about how the organisational context of a care home shapes meanings of exclusion and inclusion. The chapter evaluates in more detail the applicability of the social model of disability to understanding meanings of social exclusion in this context by exploring the impact of the physical and ideological position of each of the study sites on participants' rights and responsibilities as citizens. Discussion of data is informed by and contributes to work that is not new by merits wider currency, and that is work that calls for attention to be paid to the power of spatial and attitudinal factors in the exclusion and inclusion of people with a disability (Post, 1995; Drake, 1996; Kitchin, 1998; Gleeson, 1999).

The chapter explains how the following four factors are key to understanding how exclusionary and inclusionary processes were shaped in the context of this study; these are: locality, and in particular, where care homes were physically situated in relation to local amenities and the impact this had on individuals' access to the outside world; configuration of internal spaces and the messages these were interpreted by me to send out to people; the level of access that individuals had to places inside the care home; and fourthly, how organisational values such as 'choice' and 'home' which underpin care home life serve to shape meanings of exclusion and inclusion for people with dementia. It is argued in this chapter that many of the barriers to participation that seemed to face people with dementia involved in this study, are encountered by people with disabilities worldwide.

## 7.2 Locality

One of the most influential factors in a person's life is the locality in which they live (Bond, 1993: 200). There are different reasons for this established in the literature including the impact of locality on health (Townsend and Davidson, 1988), access to income building opportunities such as employment and education (Blunkett, 2000) and access to amenities generally including public transport and shops (Countryside Agency, 2000). From a sociological perspective, a consideration of where people live is important as 'place' is linked to matters of personal identity and a sense of belonging (Thrift, 1997). This is often the perspective taken by gerontologists in their endeavors to understand the importance of locality in peoples' lives (Reed, Roskell Payton and Bond, 1998; Kellaher, 2002).

In this section, I explore the impact of living in a care home on meanings of social exclusion and inclusion to a small group of older people with dementia. Section 5.2 of this thesis outlined where each of the study sites were located in relation to local services and amenities. The issue here is the impact that such geographies had on meanings of exclusion and inclusion to participants. It is argued in this section that meanings of exclusion and inclusion in relation to locality are highly fluid and extremely difficult to discern. Discussion shows how part of the reason for this is the different levels of locality referred to when talking about the issue in terms of social exclusion.

According to Chanan (2001: 201) there are different levels of locality to consider when exploring the meaning of social exclusion, as she explains:

'An individual maybe excluded from local society; a whole locality or neighbourhood maybe largely excluded from wealth and influence in a city or region; a whole city or region maybe somewhat excluded from national prosperity; and the pattern is evident again on a global scale with whole countries at a severe disadvantage compared with others'.

Working with this definition, meanings of social exclusion in relation to locality are considered discernable at an individual, local, regional and international level. Because of the methods traditionally used to evaluate social exclusion, as discussed in section 2.2.4 of this thesis. Researchers often investigate social exclusion at regional and international levels (Siegrist, 2000; Blackman, Brodman and Convery 2001). This small-scale qualitative study of social exclusion concentrated on meanings of exclusion and inclusion at an individual and local level. In other words, data were analysed for whether and why an individual might be excluded from their local community, and also, whether and why a care home might be excluded from the local community.

Carstairs Trust was clearly aware of the importance of locality at both these levels. Unlike the East Wing and Durlston Court, all the study sites owned and managed by Carstairs Trust were centrally located and accessible by public transport. Indeed, the geographical features of the home were included in promotional material produced by these study sites. Lulworth Court, for example, stated in its information leaflet that, 'the home is close to shops, GP surgeries, pubs and bus routes and within easy reach of the motorway'. The manager of Lulworth Court was also keen to project the home as being a part of the local community. He said, 'we are in the community, people know about Lulworth Court. We get a lot of publicity'. Lulworth Court was also very much a part of the local economy. A similar analysis was made of Encombe House. However, in this case the fluidity of exclusion and inclusion processes became evident. As a Carstairs Trust home, promotional material relating to this study site also described how accessible local services and shops were in relation to the locality of the home:

'(The home) is near to the shops, local post office and other amenities in the local village. Very near to bus routes, we are ideally situated for public transport, and are within walking distance of major superstores'

(Brochure, Encombe House).

By projecting itself as a place where the outside world could be easily accessed not only was the importance of locality in peoples' lives acknowledged, but also the geographical relationship the home had with the local community was made clear.

The complexities of locality as a factor in meanings of exclusion is further evidenced when one considers how, despite the close proximity of local shops and services to the Carstairs Trust homes, several participants who lived in one of them spoke about *not* being able to go out as often as they would like. Unfortunately, it was not always clear from the explanations that people gave why this should be so. For example, the following women all accounted for their exclusion from the outside world by describing a general sense of apprehension and fear:

I don't go out on my own – there's no point in going out on my own. I don't feel safe going out on my own

(Mrs. Phelps, age 69, Encombe House).

I can't go out anywhere. I am not safe on my own.

*Where would you like to go?*

Out for a walk...I don't go out very often

(Mrs. Winter, age 69, Lulworth Court).

I don't like going on my own (to the local shops) any more I don't feel too sure. So it is best not to do isn't it.

(Mrs. Clarke, age 80, Lulworth Court).

These women clearly felt uncomfortable about going out on their own. It was not clear, however, from what they said exactly what it was that they feared; maybe they were part of a growing number of older women who feared crime (Bernard, M., et al., 2000) or perhaps



the stigma of falling over in a public place (Horton, 2000). Either way, the fear of going out alone was that they said prevented them from doing so, and that may equally apply to older people living in their own homes. As other researchers have found, sometimes it is difficult and unhelpful to seek to attribute the constraints in peoples' lives to one single factor, like living in a care home (Reed and Payton, 1996; Oldman and Quilgars, 1999).

Other explanations that participants gave for not going out as often as they would like implicated the locality of the care home to a greater degree. For example, in the following excerpts, the first of which is taken from an interview with a case study participant and the other from a participant in the second sample group, the interchangeable use of first person singular *and* plural pronouns in these narratives (I, us, we) suggested that both these women saw their locality –that is, the care home, as well as themselves as individuals, as physically excluded from the 'outside world':

I like to go out when we can. I think it is better for us...(than) being stuck in here all the time. I want to get out – I never get out. Never shall

(Mrs. Clarke, age 80, Lulworth Court).

I would like to go down into town but I go up and down to the hospital and all that. But they are trying to organise it now so many of you can go down into town.... that is what we want to see the outside world. You see nothing only down here

(Mrs. Layman, age 80, Purbeck Lodge).

These accounts seem to accord with a recurrent theme in studies of peoples' experiences of residential care services and that is of 'not going out enough' (Townsend, 1962, Meacher, 1972, Willcocks, Peace & Kellaheer, 1987).

Being able to move freely and easily between localities is a sign of socially inclusive lifestyle (Chanan, 2001). For people who own cars and who have a mobile lifestyle this aspect of exclusion is easily overlooked (Reed, Roskell-Payton and Bond, 1998). However,

for an older person with chronic illness or disability, achieving such a lifestyle often depends on external factors such as transport, the quality of social care services, support from family members and income (Blackman, Brodman and Convery 2001). In a care home resources such as staff may be particularly scarce (as discussed in section 6.4 of this thesis) and as such an individual living in one may be more likely to be excluded from local society. Take the issue of transport; this was cited as an exclusionary factor by a number of different participants. The following excerpts are from Mrs. Clarke who was cognitively impaired and Mrs. Cheney who suffered with postural hypertension:

I used to go (to church) regularly in the older days, always have been, all my life really. I don't so much now because you can't get there in these places you know walking about miles. I can't do it

(Mrs. Clarke, age 80, Lulworth Court).

If I could go in a taxi and was better I would have gone out a bit more... It would be nice if I could just say oh I am going to go into town, but I can't do it. If I get rid of the giddiness I could walk there. It is not far away is it.... I am sure I could walk

(Mrs. Cheney, age 90 years, Purbeck Lodge).

Despite the close proximity of shops to both these homes, neither of these women considered themselves mobile enough to get there on their own. Unstable physical health would certainly be one explanation for this;<sup>27</sup> another would be a lack of transport and resources such as staff to help them. Although from a disability perspective the first would not be a problem if the latter were as accessible and as well resourced as they should be (Oliver, 1996a).

A lack of transport was also commented upon by two of three participants from Durlston Court. This care home was situated in a village, typical of the majority of small villages in

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<sup>27</sup> The impact of physical ill health is explored in Chapter 8

rural Britain today, without a shop, GP or daily bus service (The Countryside Agency, 2000). So, when Mrs. Peters was asked whether anything limited the choices that she said, 'well I have only my two feet, no car. I could get a taxi of course, which I do if necessary – to go to the doctor'. Similarly, when Mrs. Green was asked whether there was anything she would like to change about where she was living, she said, 'In a way, if I had to change or something like that, so that we can't get around so quickly. There is a lack of transport now'. These participants were clearly aware of what an influential factor transport was in their ability to move freely and easily between localities; the management at Durlston Court were equally well aware. Detailed information about where able residents might go and how they would get there was provided in the brochure for this home:

'The home provides transport to the local shops...Trips are made, for those that are able, to places of interest, and shopping excursions are made to the local towns

(Durlston Court, brochure).

The rural location of this home meant that any excursions, which were organised by the home, would have been made with other people, and probably been timetabled carefully in advance. In this way, the location of an establishment becomes a major factor in determining the nature of integration that an individual has with the world outside it (Kemeny, 1992).

Having to rely on others to help you move between localities was a clear barrier to social inclusion at a community level for many participants. As well as transport, participants with dementia for whom it would be unsafe to go any distance on their own, were also reliant on other people to go with them. A care home manager described how difficult it was from a staffing point of view, to always meet a person's request to go out:

If (Mrs. Clarke) comes up and says she wants to go into town then if we have the resources we will do it.

*The resources being?*

The resources being staff, because I am not going to sit here and say then we will go into town, because that is not realistic. Sometimes we just can't. There are other times that we can, most times we can and often she will go into town with one or two of the residents and just a key worker

(Manager of Lulworth Court).

Although Lulworth Court was on a bus route into town, someone with a cognitive impairment would need some degree of assistance to negotiate that journey, and that was not always possible to provide. Participants with dementia who faced such difficulties attempted to influence those who were in a position to help. For example, because she had difficulties accessing local amenities, Mrs. Clarke asked the interviewer if she would be able to do it on her behalf:

'I have got to take this (watch) in. I think the battery has gone in it. Someone might drop it into a shop – will they do it...because I do miss it...I think it is the battery gone, they say it is. I don't know...you don't go in (to town) do you?

(Mrs. Clarke, age 80, Lulworth Court).

In common with many people with a disability, Mrs. Clarke relies on the goodwill of others in order to get ordinary things done (Morris, 2001). Similarly, Mrs. Peters depended on others for basic supplies; for when she was asked about the type of help that she needed she replied:

'Shopping. Anyone who could help me with shopping.

*Can you ask any of the staff here?*

Well there isn't any general staff here. No if I want shopping I have to find a friend to do it for me...If someone would come and see in and see that I am always

stocked up on toilet rolls and tissues...they just don't bother about it. Is there somebody who could do that?

(Mrs. Peters, age 84, Durlston Court).

Visitors and friends clearly provide people in care homes with important links to the local community. However, for an older person with dementia who may have to move out of their local area due to regional variations in specialist provision (Audit Commission, 2002) maintaining links with family and friends may be even more problematic.

Because of the high demand for and relatively short supply of long-term social care for people with dementia, those who are deemed in need of specialist residential support are likely to be accommodated some distance away from their family, friends and local communities (Wenger, Scott and Seddon, 2002). This was certainly the case for Mr Brown, who had to move out of the town where he had grown up and where his family still lived because the local care homes were unable to meet his needs; his stepdaughter explained:

The social worker gave me a leaflet on all the nursing homes and told me to go and visit four or five and come back and say what we thought or where we would like him to go. We would have liked him to have stopped in (the town), we did say Linton House or Murray Fell but it appears that because he had got Alzheimer's' they had to have someone to look after him because of him walking about and that.... There is a residential home across the road here. He went in there at 10 o'clock in the morning and I went over. And he was out of there and across the road here...But they said they didn't think it was suitable because he would wander off you see

(Mr. Brown's stepdaughter).

The 'special needs' of someone with dementia can mean that that person has to move out of their locality in order to find the type of care they have been assessed to need. A possible consequence of this is that family and friends find it more difficult to visit, as

indeed Mr Brown's stepdaughter seemed to do, for when she was asked how often she visited her reply suggested that it was not as often as she would like:

Oh once a week, I don't drive unfortunately. I wish I did. So I have to wait for someone to take me. My husband has got a bad leg, so it is usually Saturdays and my daughter takes me and then my brother goes Sundays

(Mr. Brown's stepdaughter).

This data might suggest that the risk of exclusion from family and friends is heightened if the care home is difficult to access by public transport and located some distance from where the individual who had to move once lived. Future studies of re-location might wish to explore the effects of this apparently widespread phenomenon in the care home sector as well as precipitating factors (Cook et al. 2000).

### **7.3 The organisation of internal spaces**

The issue of space is usually discussed in dementia studies in relation to physical matter such as the style of doors and windows, the position of furniture and fixtures, the colour of carpets and corridors and the size and safety of rooms (Calkins, 1988; Kelly, 1993; Dementia Services Development Centre, 1999; Marshall, 2001). This work is important not least because it meets the needs of architects and service planners who are keen to make new builds as inclusive in design as possible (Hanson, 2002). However, the topic of space is not only an architectural one, as the way it is organised is considered 'instrumental in reproducing and sustaining disabling practices' (Kitchin, 1998: 343). This author's argument that the way internal spaces are configured sends signals to people about their place in society, merits wider currency. In this section, this idea is explored in the context of the people and places involved in this study. It is argued that the organisation of spaces sent both positive and negative signals to people about their place in society. However, positive messages were most likely to be perceived by participants without dementia.

Space availability is considered a key determinant of inclusive design (Tune and Bowie, 2000; DoH, 2001). In the Carstairs Trust homes (which were purpose built) it is possible to discern how the amount of space available sent positive messages to a number of participants. For example, Mr. and Mrs. Spinks were impressed with their personal amenities and considered themselves extremely fortunate because of it:

*Mrs. Spinks* You know it is really posh - there's a shower and cooker and its got everything. The facilities are excellent aren't they.

*Mr. Spinks* We are fortunate in one respect there is two of us because we have got two flats you see.

*Interviewer* So they have made one into a bedroom and one into a living area?

*Mr. Spinks* So we are lucky in that respect.

(Mr. and Mrs. Spinks, age 90 and 91 years, Encombe House).

This couple had access to twice as much private space as other residents and that arguably led them to feel privileged. Other participants commended the way public spaces were organised within the homes; liking the autonomy it gave them in particular:

There's a library, and I think three sitting rooms I can go to, and there's the lounge, so you can either be with people or away from them

(Mrs. Wright, age 85, Lulworth Court)

We're not all tied together in a small room. It's the space that I like

(Mrs. Wells, age 97, Lulworth Court).

The spaciousness and diversity of the living environment seemed to help these women feel as though they had a choice. The importance of internal design on the well-being of older people with dementia and other older people in this setting is noted in the literature

(Marshall 2001). Within disability studies a well-planned living environment is not only about quality of life but a basic human right which many people with a disability simply do not have (Morris, 1993; Shakespeare and Watson, 1996). In the context of this investigation, the configuration of space within the East Wing was arguably the least likely to afford people their rights in this respect.

The East Wing was a relatively newly built extension to a converted manor which claimed to specialize in the care of the 'elderly mentally ill'. The way in which this home was spatially organised was poor, radiating negative signals about the segregation of people with dementia. Mr. Brown, one of the case study participants, lived here and his room was on the ground floor immediately adjacent to the front door; the front door would only allow people to exit once a four-digit number had been entered onto a keypad. At one point during our interview Mr. Brown explained why he thought the front door would let people in but not out:

'Well they lock them from the outside door so you can't get out. And they say it is to protect one another, so that one don't clash with the other sort of thing and cause a commotion.

*And what do you think about that as a reason?*

I think that spoils the job completely.

(Mr. Brown, age 84, East Wing).

Having a front door that not everybody could easily exit from was interpreted by Mr. Brown as an effective measure for keeping people 'like him' apart from the outside world. The internal layout of the building also affected Mr. Brown's sense of self. Here he described how the lack of signage and long narrow corridors impacted on his ability to find his way around the building:



It would be no good me taking you because after about three steps I would be lost and you would have to tell me where to go. I can't I am no good at the job at all with these alleyways and up stairs and down again.

*How do you think it could be improved?*

Well I don't know if it could. Not unless you could keep it all on one floor.

*So perhaps not to have an upstairs and a downstairs?*

All the twisting and twirling round the corners....No it is good, there is nothing wrong with it at all. It is the corners for me, some of them can do it all right of course they can. Once they know where they are going they have got it all mapped out lovely, but not me

(Mr. Brown, age 84, East Wing).

Having an upstairs and downstairs and long narrow corridors, not only compounded Mr Brown's confusion; they also served to remind him of how different he was in relation to others (who could find their way around). Awareness of how we are 'placed' in relation to others is said to contribute to our sense of identity, as it raises consciousness of our moral circumstances: it makes a person think, 'this is what it is like to be me, this is who and what am I' (Shotter, 1993:122). Unfortunately for Mr. Brown, because the internal design was not 'dementia-friendly' his surroundings made him aware of how bewildered and ineffectual he was (as opposed to privileged and autonomous).

The features of a 'dementia friendly' environment have been well researched (Marshall, 1996). Authors would agree that what makes for an inclusive environment are architectural features like clarity of layout, well-lit navigable surroundings and plenty of environmental cues (Blackman, et al, 2003). From a disability perspective, what is equally important to consider is how spaces are used (as well as architecturally designed) to keep people with a disability 'in their place' (Kitchin, 1999: 345). In this study, the East Wing used the two floors it had to differentiate between those with 'advanced dementia' and those in the 'early stages' (having a room on the ground floor meant that Mr. Brown was clearly seen

as a member of the latter group). Here, the manager described the rationale for dividing residents up in this way:

I do have a sort of deliberate strategy but it doesn't always work that way. It does depend on demand and supply. For example that new man ... the general thing is that upstairs is for the more advanced dementia. But we do have a man – two people in the early stages with dementia but we bring them down as soon as they are dressed and they have had their breakfast in the morning - downstairs.

*And what is the sort of rationale behind that?*

Because there is more happening downstairs, there is more people coming or going, they are downstairs right beside the garden, they can go out into the garden that sort of thing. Although the design of that place is that there are long corridors upstairs and downstairs so they can walk around as much as they like but I just feel they are better off downstairs. The activities room is downstairs, the activity coordinator goes upstairs and downstairs. She does activities upstairs as well. But I just feel it is more healthy for these people with some limited insight to be on the ground floor

(Manager, East Wing).

It might be suggested that the spatial segregation of residents in this home led to a subgroup of people with dementia who were even more likely to be excluded from the ebb and flow of everyday life. Moreover, the subgroup of people with dementia created as a result of the way space was organised in this home were arguably living in conditions of social deprivation. Scott, (1994: 151) explains, 'deprivation involves exclusion from the full rights of citizenship, and most particularly, from its social component. Thus, spatial relations in this home might be interpreted as working to tell people most affected by dementia (and care workers and visitors) not only that this group of people are not important but also that they have no social rights as citizens.

Hanson (2001: 178) argues that the uniformly poor design of buildings has created an 'architectural disability' for many thousands of older people who require some form of supported living arrangement. In the case of the East Wing it is possible to see how the seriously misguided design and use of space also sends signals about the value of people

with dementia. Certain standards in relation to the design features of a residential care home are common to all care homes and must be met (DoH, 2001). These include the amount and quality of communal and private spaces, lavatory and washing facilities and adaptations and equipment that a person living in a home can expect to have. Of all the environmental standards introduced by Government, the spatial dimensions of communal and private areas has caused most controversy, as many care home owners feel that they are not sufficiently funded to make the structural changes necessary to their premises to meet such standards (Guardian, 2001). Consequently, Government has recently revised standards relating to spatial dimensions while at the same restating its commitment to raising environmental standards within residential care homes (DoH, 2003). The politicisation of space within this type of residence is an influential factor in the exclusion and inclusion of older people with dementia in care homes. This is because it can lead care homeowners to marginalise the spatial needs of people affected by dementia.

At the time of this study, the proprietor/manager of Durlston Court was waiting to hear from inspectors whether or not they had ‘enough day space’<sup>28</sup>. Consequently, in our interview she spoke of the spatial needs of residents:

I think it is important that people have enough room, that they are not pushed in but I am sure there is some very good care where some people only use there bedrooms to sleep in, in which case do they really need such a big room? And certainly people with dementia, we went upstairs, [...] has just gone upstairs now, but there will be no one up there, they will be all down in the sitting areas. Some people will stay in their rooms or go back to their rooms, they have the choice but a lot of people want to be with people and want to be assured to be with people so to have private places, when we are short of beds for such people, it is rather hard

(Manager, Durlston Court).

This care home owners view seemed to be that the amount of physical space that a person has does not in itself ensure quality care. Indeed, the view that care practices rather than

care setting is most critical to inclusion is supported in the literature (Blackman, Brodhurst and Convery, 2001; Marshall, 2001). Given the economic implications of making certain every resident has a set amount of private and communal space, representing people with dementia as a group who do not generally need or use space in the same way as other people, no doubt makes sense to this manager. The frustration that care home owners feel about building regulations which, for instance, demand more bathrooms in a building than there are staff to bathe residents, is argued to be understandable. Nevertheless, the view that people with dementia have broadly the same spatial needs, not only denies the individuality of those affected by dementia, it also fails to take account of the role that places play in the construction and maintenance of social identity (Kellaheer, 2001). It is to this issue discussion now turns.

#### **7.4 Levels of access**

There is an erudite body of gerontological literature underlying which is the fundamental assumption that the fewer spaces a person has the fewer opportunities they have to express themselves (Willcocks, Peace, and Kellaheer 1987; Peace and Johnson, 1998; Peace and Holland, 2001). This theory has informed housing and social care policy in relation to older people; consequently, proprietors of residential care homes are expected to make sure that 'homes are for living in' and more recently that service users have access to areas in which a wide variety of social, cultural and religious activities can take place (DoH, 1989, DoH, 2001). Given the concerns of this study, the main focus of analysis was on what level of access people with dementia had to various places, and, whether that level was equal to what other residents in the home had.

Netten (1993) found in her study of thirteen care homes that residents with dementia had less privacy and freedom of movement within the home as other residents. A similar observation might be made about the level of access afforded to residents with dementia in

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<sup>28</sup> Durlston Court used to be a manor house in which the manager and her husband lived. They converted it in 1987 to accommodate older people with mental health needs.

Encombe House. One of the statements used to facilitate focus group discussions in this study was 'wearing a call alarm so you can alert someone if you fall'. The assumption was that should a person fall and need help they would not necessarily be in a place where staff would see them. Discussion within one group about this statement revealed how unlikely this was for a person with dementia, as these people tended to be in the same place most of the day:

Ms. E.           The majority of the dementia people here I mean we are with them most of the time, they are in sight aren't they, they are in view, and we keep an eye out for them don't we.

Ms. B.           So that is how we overcome any potential hazards really.

Ms. E           Yes.

Ms. E.           It is just safety isn't it to keep an eye on them.

*Moderator*    *So they are always within a public area?*

Ms. E.           Yes, generally.

Ms. B.           Well we try to keep them (in the lounge). We don't like them to be in their flats on their own because they need interaction; they need someone there which is quite nice.

(Care workers, Encombe House)

The safety and social needs of people with dementia were considered best met by restricting people to the lounge area. This was not the case for other residents in the home however, as elsewhere in the discussion about the call alarm Ms. B. said how frequently staff moved around the building and so would quickly find anyone in need of help. In addition to which, 'the residents look out for each other as well' said Ms. E., offering a further example of an alternative way in which the safety and social needs of other residents are met. From a Foucauldian perspective, this account of how certain people – that is, those 'with dementia' - are brought into a field of visibility so that staff can observe and monitor is a central strategy of disciplinary power (Lupton, 1997). In this instance, the

exercise of such power excluded some people with dementia from certain 'benefits of membership' to the home such as access to spaces and places beyond the lounge (Jordan, 1996:5).

Equal access is a key feature of an enabling environment (Johnstone, 2001).

Exclusion can result from not being able to do as you wish or go where you please. Due to the nature of dementia, a person affected may well be restricted from going where they pleased, often to minimize the risk of the ultimate social exclusion: death. The Environmental Health Officer described how common but uncomfortable it was for him to see this happening:

I felt really sorry for this one woman because I was leaving, they let me out this gate and this woman was so desperate to get out she was saying please let me out and they couldn't let her out so it is distressing and it is not nice to see. You have to be cruel to be kind in these home.

(Environmental Health Officer).

The Environmental Health Officer clearly 'felt' for this woman's exclusion from the outside world, but what of her right to liberty? (Human Rights Act, 1998). The infringement of civil rights based on the welfare of people with a disability is seen as a form of oppression (Oliver, 1996a). However, this argument is based on the assumption that that person with a disability has the capacity to make calculated risk for themselves. Clearly if someone is cognitively impaired then that might be extremely difficult if not impossible for them to do. Thus, people affected often have to rely on the risk perceptions of others who determine for them (usually following a risk assessment) how much access they can safely have to different areas and activities (Clarke, 2000). The lack of consideration within the social model of disability to mental health issues was noted in Chapter Three and is discussed further in Chapter Ten. The point to make here is that although barriers imposed by others (such as a locked door or a risk assessment) might

restrict the level of access a person with dementia has to some places, they can mean less chance of more severe forms of exclusion.

In other study sites, spaces and places beyond the lounge were said to be accessible for all residents. The statement 'choosing how to spend the day' prompted the following discussion amongst care workers at Lulworth Court. From this conversation, it was clear that certain residents were able to go where they pleased, namely those 'with their faculties', and that different people chose to spend their time in a variety of places. However, what was not clear was what level of support those with dementia would receive in order to do the same:

Ms. S            For those who have still got their faculties then I should think that is important to them really, to do whatever they wish during the day.

*Moderator    But for people who don't have the capacity to choose.*

Ms. S            Well you like help them don't you.

Ms. T            Some residents like to stay in their own flats, watch television, do their own thing that's quite all right. Some stay in the big lounge and we have television, may be videos or some entertainment for them. But sometimes they just like to sit quietly looking at magazines and to see what is going on. People coming and people going out and there is a lot of going on through the day and they just like to watch.

Ms. T            There are quite a lot who don't - they don't seem to do anything. But they take note of what is going on and of course they wait for each mealtime don't they. Each mealtime is a social event. They go to the dining room and come back and it is a bit of disturbance during the day. Some go to the shop, we take them to the shop and back and they do their own shopping.

Ms. C            They should be allowed to choose what they want to do.

Ms. T            They should be yes.

(Care workers, Lulworth Court)

These care workers seemed to see residents of Lulworth Court as a group of individuals with different spatial needs and leisure interests. For those who were able to choose for themselves how to spend their day, these needs were seen as being generally well met. For other residents though, staff help was identified as an influential factor in making places accessible. The manager of this study site shed some light on how able the organisation was to provide the help that people needed. He said, 'whether people can do what they would like to because of the risk involved, certainly in walking up the road and we like plenty of activities and people to join in but again it is down to the staffing levels'.

## **7.5 Organisational values**

From a disability perspective, the values underpinning an organisation are important to consider as they have the potential to 'perpetuate existing relationships of power' (Priestly, 1999:31). Within a care home environment, planners and providers of care are often in a commanding position to promote and impose certain values and standards for those in receipt of services (Drake, 1999). In this section, the values that underpin the study sites are presented and put forward as influential in the social exclusion and inclusion of older people with dementia in residential care.

### **7.5.1 Independence**

Government policy aimed at supporting people with long-term illness or disability is based on the principle and promotion of independence (DoH, 1999; DETR, 2001). In this context, 'independence' is taken to mean that a person either has no need for care or support (Audit Commission, 2000) or financial assistance from the state (Dowling, 1999). The problematic nature of this definition of 'independence' has been discussed elsewhere in this thesis, and in particular, it was suggested in section 2.3.2 of this thesis that a low priority might be given to older people with dementia in care homes, and others in need of long term care, if Government concentrate efforts and resources in promoting independence (Cantley, 2001) based on this definition one could add. In this section, the



value and meaning of independence to both the individuals and the organisations and that took part in this study is explored. It is argued that the simple dichotomy of independence and dependence that Government endorses shapes meanings of exclusion by simplifying and reducing peoples' status and capacity as citizens.

A key aspect of the duty of a citizen is to take responsibility for themselves where they can (Burden and Hamm, 2001). This aspect of being citizen seemed to be important to several participants, but from what was said, very difficult to achieve in a practical sense. Take for example, the situation of Mrs. Milner who was registered blind and unable to mobilise due to chronic osteoarthritis; this is how she responded to a question about what independence means to her:

To be able to do things for myself instead of having to worry anybody I'd like to be able to walk to get the things. I think if something is wrong, if only I could walk, but I can't. (My health) has not been too good since I had the fall - that was the climax you know.

Mrs. Milner clearly wished that she did not need other peoples' help, but poor physical ill health meant that reliance on others was unavoidable. Similarly, another woman in this care home, who was able to mobilise but needed some help with grooming, revealed what independence meant to her:

Well walking along here on my own and go to the toilet on my own.

*So doing things on your own then?*

I have got to the stage now I can't brush my hair properly, so they do that for me when I am getting dressed of a morning. Put the comb through, oh they are quite nice crowd of people here.

(Mrs. Layder, age 80 years, Lulworth Court)

These two women responded to a question about independence by describing physical movements that they were and were not able to do.

It is argued that because society sees independence as the ideal; dependence conveys weakness and failure (Redfern, 1997). The effect of the emphasis on independence is that people with dementia and other people who are unable to do everything for themselves come to be seen by others as 'second class citizens'. This is how Mr. and Mrs. Spink described others in the home:

*Mrs. Spinks* (My husband) washes and shaves and all that. But some of the people here they have to do all that for them....

*Mr. Spinks* Well, we can do most things for ourselves, but a lot of them won't do things for themselves that is the trouble. It's not that they can't they won't.

*Mrs. Spinks* Like tidying up the table or something like that. They leave it all for the girls.

*Mr. Spinks* They even have tea brought up to them. We have never had a cup of tea brought up to us in the evening. But we see the dirty cups left outside for them to collect in the morning. They don't even wash the bloody cups up.

*Mrs. Spinks* You know you could carry them down with you couldn't you.

(Mr and Mrs. Spinks, age 90 and 91 years, Encombe House)

Each of the organisations that took part in this study reflected a different degree of importance and achievability of this for the people living in their care homes. For example, the Carstairs Trust Homes were all governed by policies and procedures which emphasised people's rights and responsibilities as citizens, including the 'right to independence'. Similarly, Durlston Court portrayed the importance it placed on independence by explicitly stating in its information leaflet how this was an expectation of individuals. It read, 'our residents are encouraged to be as independent as possible, with help and reassurance given as required'. Perhaps because this care home catered specifically for older people with dementia it assumed some degree of assistance would be required by an individual to be

‘independent’. An attitude that ardent advocates of the social model of disability would perhaps describe as paternalistic (Oliver and Barnes, 1993: 274).

By contrast, the information leaflet produced by the East Wing – the nursing home – did not refer to *independence* at all. Instead it seemed to assume that prospective service users would ‘inevitably be frail, dependent and incapable of making decisions in their own interest’ (Thompson and Thompson, 2001: 63). It stated that, ‘the home provides safe, comfortable and secure care for *the elderly mentally ill*’ (my emphasis), and in a section about ‘support for relatives’ that, ‘*elderly dependent* relatives are looked after by evening staff’ (my emphasis again). The problem with these phrases is twofold. First, it denies diversity and difference amongst those living there and negative assumptions about them are at the same time projected (Fawcett, 2000). Second, it places a structural limitation on peoples’ rights – that is, a person is afforded no means by which ‘to exercise citizenship rights’ (Walmsley, 1993: 262).

According to Gibson (1998) the dependency of older people is structured indirectly by service providers who exclude older people from various social responsibilities and activities. Holstein and Gubrium (2000:1) suggest that others often do see and treat older people as a homogenous group who like to ‘indulge themselves in leisure and recreation activities’ rather than more industrious pursuits like work or training. This stereotypical image of ‘old people’ as passive and anti-work seemed to inform the way in which some of the study sites organised activities. It is now a National Minimum Standard that care homes give prospective service users a brochure, which outlines (amongst other things) what the home has to offer in the way of mainstream activities (DoH, 2001). Such documents thus revealed not only the types of opportunity made available to participants, but also, and more critically from the perspective of this study, what service providers considered appropriate for this client group to be choosing from. In terms of the type of activities that an older person coming into a home might like to be involved in, the

following three excerpts show how gentle leisure-type activities were consistently assumed to be central in an older person's life:

The types of activities undertaken include painting, singing and videos of the Royal family...

(Brochure, Durlston Court)

Social and recreational activities are important for providing quality of life and we organise social events, shopping trips, theatre visits and outings as well as visiting entertainers. We provide a range of activities which include reminiscence therapy, art therapy, board games, community singing, cooking, gardening, clay-modelling, sewing and other handicrafts

(Brochure, East Wing).

Activities currently available for you to enjoy include: theatre visits and day trips, table top games and quiz nights; fundraising events and clothes parties

(Brochure, Carstairs Homes).

By anticipating the interests of prospective service users, each organisation revealed what it thought older people liked to do, and risk-free pursuits, particularly theatre visits and singing were top of the list. Aside from the Carstairs brochure, with its inclusion of fundraising, there was no mention of an activity which Burchardt, Le Grand and Piachaud (1999) would define as either socially or economical valued, or political in nature. Most significantly, there was no mention of an activity that would allow expression of a more powerful or authoritative identity for an older person with dementia or other people living in this environment, such as having in say in the day to day management of the home, training or work opportunities, political campaigning or participating in society more generally. That is not to argue that a person living in one of the study sites would not be able or supported to be involved in such pursuits, but that each of the study sites assumed prospective service users would not want to, because they had categorised them as 'old'.

The 'structured dependency' of older people as a result of systems evoked by younger people is discussed in the literature (Townsend, 1981; Walker, 1993; Vincent, 1995, 2000). In the context of this small-scale study, the main problem with assuming that 'old people' are people who like to take things easy is that this then affords participants limited or no opportunity to do or be something that is of social and/or economic value. Indeed, three of the fifteen participants from the second sample group spoke directly of exclusion from this particular mainstream activity<sup>29</sup>. The point to make here, though, is that simply because a person is of a certain chronological age, does not mean to say that that person will *necessarily* prefer a sedentary lifestyle; older adults have the same range of tastes and potential as their younger counterpart, and so categorising a person as 'old' delimits the range of opportunities made available to them (Tinker, 1997a).

From a sociological perspective, a care home operates as a care home only if the actors involved draw on the implicit and explicit rules that structure care home life (Giddens, 1991). Having only moved into the care home a week before the interview took place, Mrs. James was still acclimatising to its rules and routines. Her account of how she did not complain about one particular care practice, even though it annoyed her considerably, provided further evidence of the extent to which power and control is mediated through routine:

'This morning because I was a bit late I had my eye drops – my eye drops with my Cornflakes – I was given my Cornflakes and they said can I do your eye drops now. And I said yes of course you can. But then I had a spoonful of Cornflakes in my hand. They often do that, now I don't like that.

*Would you ask them to wait?*

they do it to everybody so I think well this is the done thing, I must abide by it. I don't know it's not much is it...I am not the only one of course. But I thought well why doesn't somebody talk about this...I think they are so fussy about some things but why do we have to have eye drops and Cornflakes too

(Mrs. James, age 90 years, Purbeck Lodge).

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<sup>29</sup> Individual experiences of social exclusion are discussed in Chapter 9.

The indignation that Mrs. James experienced about having to have her eye drops administered while in the middle of her breakfast was secondary to the routine of them being administered at breakfast time. It was when Mrs. James said how she felt about being told not to do something that the potential impact of such a request on a person's sense of identity became clear:

I have been told since I have been here I have had three or four falls and now I have been told specifically not to move from my chair unless I have someone with me, so I have to sit a lot.

*How does that feel being told not to move?*

Oh awful. It is not me at all

(Mrs. James, age 90 years, Purbeck Lodge).

Being told what to do took away any responsibility that she had for herself, moreover, it seemed to lead her to feel different to the person she was. Further examples of being told what to do were given by participants with dementia. For instance, Mrs. Clarke said, 'I mustn't go out on my own, I have been told I mustn't and Mr. Smith said that he had been told to accept his poor vision. What is significant with these accounts is not so much what people have been instructed not to do, but that participants describe it in this way: being 'told' to do something, as though they had no say in the matter at all. Assuming this is the case, it suggests another influential factor in the process of exclusion, because as Shotter (136) says, 'to live under terms set only by others is always to feel not just different but inadequate in relation to those others'.

### **7.5.2 Home**

The model of service delivery on which a care home is based has major implications for the way that care home is managed and run (Bland, 1999). The ideal advanced as a basis for residential care is that of 'home' (Higgins, 1989; Peace and Holland, 2001). In the

context of this study, the value of 'home' on which each of the study sites was based, shaped meanings of exclusion and inclusion by imposing onto residents the idea that the care home was now their 'home' and that such a construct was both achievable in reality and a universal desirable place to be (Shurmer-Smith and Harman, 1999; Gibson, 1999). It is argued in this section that this was exclusionary because it meant other perceptions of what a care home is for (such as, to convalesce) were marginalised, and inclusionary as it aimed to engender a sense of community and belonging for people living there.

Moving into a care home might be described as a type of 'exclusion through segregation or differentiated inclusion' (Ravaud and Stiker, 2001: 504). This is because, while physically part of a community, a residential care home exists to separate and house certain 'types' of people – in the context of this study, older people with dementia – away from others who live in that community. The complex and contradictory role that a care home has to play in an older person's life was commented upon by one of the care home managers when she was asked whether residents' missed out on everyday life by being in a care home:

Of course they do yes.

*What sort of thing?*

Although when you look at where these people came from they are often very isolated by the time they get here and very lonely and when they come here they pick up because they have got people around them, they have got people who are kind looking after them

(Manager, East Wing).

One of the ways in which the residential care homes involved in this study imposed onto residents the idea that a residential care home was now their 'home' was by downplaying the organisational identity of a care home:

I don't see it being a Home – I mean I know it is a residential place but I don't see it as being a Home, I think it is more a home from home

(Care worker, Lulworth Court).

Even though the dwelling to which the care worker referred, accommodated up to forty people, describing it as 'home from home' was a way of claiming and reiterating what it claims as its core characteristic, namely a place not unlike a person's own home. The care worker made it clear to me at this point that Lulworth Court was not to be perceived of as an 'institution' in which people are restricted but as a 'home' where a person is free to live as they choose. In addition, the care worker's observation that Mrs. Clarke was 'starting to be part of the family' highlighted the fact that a care home is not just a physical place but also a social system involving other people and relationships. These perceptions suggested that a consequence of defining a care home, as a 'home from home' was that people, who did live in this particular kind of community, were expected to value and/or need certain 'things', most notably a family.

(Lulworth Court) is not an institutional type of place where (people) have to sit in their room all day, so (Mrs. Clark) is still allowed her freedom here as well as she would be at home. I think (Mrs. Clark) is starting to be part of the family here, which is what we call this place

(care worker, Lulworth Court).

The belief that a care home was as a homely place was also a seemingly desired outcome of written portrayals of care home life. The following excerpts are taken from documents pertaining to each of the study sites; note in particular, how staff are universally invested with the responsibility of making a care home the cordial place that service providers hope it to be:

The emphasis is on providing a family atmosphere; it is more like a home than a Home..(the manager) hopes that residents will look at Durlston Court as their home.



(Brochure, Durlston Court).

Staff who work with residents will help to produce an atmosphere which is homely, cheerful and relaxed at all time.

(Carstairs Trust, Residents Charter).

It is the quality of our staff that makes our home special...The cheerfulness and dedication of the staff provides a friendly homely atmosphere

(Brochure, East Wing).

Each organisation was understandably keen to portray itself as a positive and pleasant place for people to be, and care staff were seen to have a key part to play in the creation of that experience. The assumption that a constant 'sphere of harmonious social relationships' is vital and indeed possible within this (or indeed any) type of residence highlights how the mobilisation of one ideal – that of homeliness – can define the form and function of a place (Crow and MacLean, 2000: 240).

According to Gurney and Means (1993) the assumptions that underlie organisational definitions of home are to be carefully examined and compared with the meanings that older people themselves give to living in a care home. In the context of this study, analysis of the meanings that people living in a care home ascribed to that experience revealed how different their perceptions were of what a care home was for.

It is my home, it is my home now, I am quite. I do see it as the place I live and I am happy.

*And what makes it a home for you?*

It has got that sort of atmosphere about it. We all seem to be family and the ones of us that are out will talk about our worries and compare notes sort of thing and it is quite friendly. Unfortunately there are not many here that are able to have a reasonable conversation with. Lots of them are demented and some of it is Alzheimer's I think

(Mrs. Housel, age 74 years, Encombe House).

Unlike the organisation, Mrs. Housel saw certain other residents as key players in the creation of a homely atmosphere. However, because that process was dependent on talk, those who were less able to communicate missed out on being seen as creators of that 'atmosphere'. While the organisations used the concept of 'home' to convey the model of care that service delivery was based upon, participants who lived in a care home mobilised the same concept but for different reasons. Several participants, for example, spoke as if where they were was not a 'real' home at all:

Oh, I settled in very well. It's not home, you can't pretend it's home, but it's as good as you get away from your own home. So no, I've no complaints really

(Mrs. Wells, age 97 years, Lulworth Court)

Well people say there is nothing like home and I lean that way a bit. There isn't anything like home is there where ever you go it is lovely coming back home

(Mr. Brown, age 84 years, East Wing).

In these accounts the concept of 'home' was mobilised to convey the *difference* between a residential care home and 'home'. Other participants with dementia were inclined to see the residential care home as a type of organisation rather than as a 'home'. For Mrs. Dryden, Encombe House functioned more like an intermediate care service – that is, as a place to recuperate and recover; she said, 'I had a stroke and came here for a holiday, to have a rest'. It was not a place she seemed to regard as her home because she said that what remained important in her life was her family, children, and 'of course, my home'. Similarly, Mrs. Green said that she would rather live somewhere else, as when asked what

she thought of Durlston Court, she said, 'I wouldn't live here I would get myself a little cottage'. Others were clearly aware of the hierarchal structure that befits an organisation, as Mrs. Larkin asked at one point during the interview, 'someone here is in charge of looking after all this is that you?' Obviously these perceptions of what a residential care home is for and how they work may reflect the experience of these people's lives; nevertheless such remarks indicate the extent to which the meanings that service users attach to living in a residential care home differ substantially from those of service providers. As Drake (1999) points out, the problem with this is that the perceptions of the more powerful group usually prevail while those of service users become subordinate.

The dominance of organisational perceptions of care home life and the impact that that has on the identity of residents was evidenced in this study during a discussion with one of the managers of a Carstairs Trust home. The discussion, which arose in response to a question about how the home helped people to lead an active life, reveals how the meanings that service users attach to living in a care home can easily be construed as inferior compared to those of the organisation; here she described why she often found it difficult to get some people to live an active life:

They want everything to be organised for them they don't like to do things for themselves– I have tried to get them to – but no they just sit back – and some are more able than others. Or we have got things set up and left but they don't want that they want somebody there telling them what to do.

*Is that because of the environment?*

Yes, but I think a lot of them think well I pay so...

(Manager, Encombe House).

This manager found it hard to adhere to certain organisational values (such as independence) because she believed people moving into Encombe House viewed the place more like a 'hotel' than a home in which they would normally be active and autonomous. Oldman, Quilgars and Carlisle (1997) also found in their study of care homes that several

residents perceived the organisation to be a 'hotel' and were equally reluctant to do things for themselves. The problem with this attitude, and why it shapes meanings of exclusion, is that it stems from the mistaken belief that 'independence' is possible. As Johnson (1993: 257) points out, there is 'no one who in any proper sense is independent', as we all rely on each other to a certain degree.

#### **7.4.2 Choice**

The notion of 'choice' is widely used but ill defined. From a policy perspective, choice is identified as the opportunity to select independently from a range of options and is increasingly seen as a central part of the inclusion process (DOH, 1989; DoH, 2000). From a disability perspective, the idea that people have a choice at all is doubted because a person with a disability often has to choose from options, which are not options they would choose to choose from anyway (Wareing and Newell, 2002). In addition, the social exclusion literature debates whether anyone has a right to choose to self-exclude. The problematic nature of the concept becomes clear then; even more so when we realise that there is no certain way of distinguishing actions involving choice from other actions or behaviors (Barnes, 2000). In this section, the notion of 'choice' is examined as a social construct - that is, as a mechanism for creating the semblance of inclusion.

One of the principle methods that care workers used for constructing the notion of choice was through the use of language and words. In the care homes belonging to Carstairs Trust, this method was widely used. For example, choice was one of the six issues identified on the Charter of Rights produced for residents (the others related to: staff; care practices; privacy and dignity; social life and quality of buildings). This meant that every care home pledged to achieve certain standards in respect of personal choice, including, 'allowing residents to accept or reject whatever is on offer including medication, treatment or care practices' and 'giving residents the opportunity to review and advise on menus, menu changes and food presentation'. Other items were written in a similar permission giving style. The Charter also identified several specific areas of choice (such as when and

where to eat, when to bathe and times of going to bed and rising), which could be exercised at the resident's discretion. Within the context of written performance standards, then, the notion of choice was constituted upon the ordinary if not mundane aspects of everyday life, which in any other setting would probably not be considered a choice at all, but in the communal living environment of a care home are considered very important indeed (Parsloe, 1997). However, from a disability perspective, the problem with this process, and why people living in a care home actually fail to have a choice at all, is that this Charter was produced *for* residents rather than by residents and so non-disabled people rather than those who lived in the care homes controlled what should be included and excluded as constituting choice (Drake, 1996).

Another way in which care staff in the Carstairs Trust homes constructed the notion of 'choice' was by writing care plans using a particular grammatical style. The home care manager of Lulworth Court explained how just by switching pronouns a greater sense of individual choice could be conveyed in a person's care plan:

Mrs. Clarke would dictate exactly what she wants put in (her care plan). So that instead of being written in the third person it would be written in the first so Mrs. Clarke would be saying I would like this, this is how I want my life to be within the home, I want meat and veg. for lunch or I don't

(Manager of Lulworth Court).

This practice suggested to me that the way in which things are written are thought to have an impact on the way in which they are perceived. Once again though, choice was constituted upon ordinary activities that go on 'within the care home' and so what Mrs. Clarke had to choose from was what other people said that there was to choose from (such as food). In this sense there was not necessarily any choice at all as what constitutes as a 'choice' for one person may not count as one for another. Indeed, when Mrs. Clarke was asked during her interview what she liked to eat, she replied, 'well we have what is given us don't we dear'. For the concept of choice to be meaningful a person not only has to have a wide range of options to choose from, but also, those options need to be of a type that people want to select from (Nolan, et al, 1996).

A third mechanism for constructing the notion of choice involved making the options on offer sound as exciting as possible and the sort of thing that a person would want to do. One manager described how by wording things in the right way people were more likely to choose from the options available:

It is how it is put to them, like anything, like when we do a lot of activities; it is how it is put across to them. If it is put across well what do you want to do, you get nothing, but if it is put across with a great deal of enthusiasm then the residents will go with you

(Manager, Lulworth Court).

The approach taken by the person providing the choice has an impact on the person who is expected to take up that choice. Although such a strategy might then lead to more people getting involved in a scheduled activity it might not necessarily mean that they *feel* included as a result: when Mrs. Windsor of Lulworth Court, a participant from the first sample group, was asked whether she likes to take part in the art classes, she replied, 'well they come and ask me and I can't say no. *Why not?* I don't know', she said. In this instance, the choice is not about whether or not to join in an art class but whether or not to refuse or passively accept the offer.

Someone else might equally choose the latter option, as seemed to be the case for Mrs. Green:

We would ask her if she wants to join us, would you like to join us, we are going to do this this afternoon would you like to come and do it as well. Would you like to come and help us take tea round or whatever. And she can definitely say yes or no.

*So she would make her own choice.*

Yes. She is quite definite about what she wants to do or doesn't want to do

(Manager of Durlston Court, talking about Mrs. Green).

Wording things in the right way, in this instance, meant stating what peoples' options are, and then that person chooses from one of them accordingly. Two care workers highlighted the importance of 'wording things in the right way' when they discussed the possible consequences of simply asking someone like Mrs. Green what they would like to do:

Ms. P            I mean if you actually gave them the choice - like Mrs. Green - if we said what would you like to do today she would say oh I'd love to go home. And that isn't possible, so I don't think you can give her the choice of what she would like to do.

Ms. S            Not give her such a choice.

Ms. D            You can guide her a lot. You can suggest and guide but you can't actually give them a choice— because that is why they are with us because there was problems.

(Care workers, Durlston Court).

It would seem that because Mrs. Green's 'problems' were all assumed to be a direct result of her impairment, care workers avoided asking her open ended questions about what she would like to do, and instead worded things in the right way, thus ensuring she only chose from those options deemed appropriate for her. This approach to choice making is described in the literature as 'positive autonomy', in that others interfere with individual choices so that meaningful choices can be made (Hegeman and Tobin, 1988: 75). In the context of this study, it highlights how influential the attitudes and language of staff are in shaping peoples' opportunities. This is consistent with a previous study by Joseph Rowntree Foundation (1999) who also found that while most participants (who were people with dementia and downs syndrome) had choice about everyday activities, participants actually had little if any choice over the running of the care home or major life changing decisions.

## **7.6 Summary**

This chapter has examined some of the organisational dimensions of social exclusion in the context of this small-scale study. In particular, the chapter has focused on how powerful the signals are in relation to geography and philosophy of each of the care homes impacted on participants' ability to have a say in the ethos of the home. Discussion has revealed how difficult it is to discern the source of exclusionary processes in certain circumstances. For example, some of the reasons participants gave for not going out as often as they would like might equally apply to older adults in private households. So, what might appear to be a fairly straightforward explanation for exclusion processes might actually be quite complex.

This led to the argument about how the issue of space is also multifaceted: spaces do not simply accommodate people, the configuration of them also send signals about the value of people. The unequal treatment of people was also highlighted by the discussion about levels of access. In one of the Carstairs Homes, the rights of people with dementia to be alone were marginalised because everybody was perceived to need interaction. The values underpinning the care homes that took part in this study were also put forward as evidence of the power that service providers have over service users.



## CHAPTER EIGHT

### The Organisational Context II: routines, language, attitudes and relationships.

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#### 8.1 Introduction

This chapter is the second to address the research question about how the organisational context of a care home shapes meanings of exclusion and inclusion. The chapter continues to explore the relevance of the social model of disability, by focusing on how the cultural characteristics of each of the care homes involved in this study impacted on participants' rights and responsibilities as citizens. *From a disability perspective, the culture of an organisation is important to consider as it is often this which marks out people with impairment as inherently different and undesirable (Marks, 1999a).* Arguably, this then becomes the main source of power that some individuals and communities have to exclude others (Byrne, 1990).

Discussion focuses on the main cultural characteristics of an organisation described in the literature, including: routines and regulations (Goffman, 1968; Giddens, 1991); language (Adams, 1999; Marks, 2001); attitudes (Becker, 1963; Byrne, 1999; Bond, 2000) and power dynamics in caring relationships (Meacher, 1972; Fox, 1993, 1995; Fulton, 1997). In sum, the 'relations of ruling' – or, the situations in which individuals are both active in creating and also governed by (Smith, 1990).

#### 8.2 Organisational routines and regulations

The routines and regulations which characterise an organisation like a care home are well researched. Despite attempts by service providers to make a care home a 'home, the reality is that life inside a home is routinised and subject to regulatory requirements (Willcocks, Peace and Kellaher, 1987; Peace and Holland, 2001). It is argued that routines and

regulations shaped meanings of exclusion and inclusion by creating an inherent tension between what is desirable and what is achievable.

Residential care homes are required by law to act in accordance with certain regulations. One of the main areas of legislation for the residential care home sector is The Health and Safety at Work Act 1974; The Management of Health and Safety at Work Regulations 1992 and The Control of Substances Hazardous to Health Regulations 1994. Broadly speaking, this body of legislation is designed to protect those who work in and visit residential care homes as opposed to those who live there<sup>30</sup>; so, as well as functioning as a 'home', this type of residence is also very much a workplace. The Environmental Health Officer communicated this in no uncertain terms when he described what he saw as the main characteristics of a care home: 'any care home must be safe, must be regularly inspected and there must be records... it is a place of work'. In his view, the regulatory framework underpinning care home life made a care home not like a 'home' but like a place of work. The conflicting purpose of a residential care home is clearly an important factor to consider when seeking to understand the meaning of social exclusion in this context, not least, because of the tensions it creates whenever care staff seek to involve people with dementia in mainstream domestic activities such as cooking and cleaning.

Due to health and safety considerations, residential care homes are expected to find alternative ways of maintaining peoples' involvement in everyday tasks – for example through the provision of kitchenettes or organised cooking clubs (DoH, 2000). From data collected for this study, Durlston Court seemed to be most innovative in this respect; significantly, it was the place where tensions about regulatory requirements seemed most acute. Compare the following accounts about a person with dementia being involved in domestic activities; the first is from the manager who describes the types of everyday tasks that Mrs. Green liked to be involved in around the home:

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<sup>30</sup> The Environmental Health Officer supplied written information about this body of legislation.

I am trying to get (Mrs. Green) to be more independent, trying to encourage her – they have trays with toast on them, different pots and cups and coffee and tea and getting them to pour out for themselves. Obviously when people come into a home they do lose some independence because they have taken away first of all by preparing the meals for them. When they may only have a little bit, environmental health people aren't over keen that they should do too much. So some of it has already gone, they don't even clean their rooms. They wouldn't do more than dust around in their room and I consider that is part and parcel of being here. So some of the independence has already gone hasn't it, so we are trying to maintain that. What else? (Mrs. Green) likes to help with the tea trolleys and help give the biscuits out. And she likes to come in the kitchen and likes to help us wash up. She can rinse things and possibly dry things but we have to put them through the machine

(Manager of Durlston Court, talking about Mrs. Green).

The manager is clearly aware of how important basic tasks such as cooking and cleaning are to a person's identity; hence, she is flexible in her approach as to who carries out some domestic chores and where a person with dementia can go within the home. Conversely, the Environmental Health Officer was dismayed by the way that some care homes - like Durlston Court, not only use kitchens which have been adapted but also allow people with dementia to access them:

It is amazing some people – you walk in some of these care homes and they have actually converted their own personal kitchens into what they think is appropriate and I go there and I think it is not very appropriate... in dementia I feel (people affected) need a lot of care. I honestly do. And the health and safety – they have got wandering and all sorts and you can go into places and nose in the kitchens and they are there trying to make themselves a cup of tea and stuff in areas with sharp knives. It can be quite hazardous in a way. And then they go wandering off outside, so you need a lot – so you need a lot more risk assessments.

(Environmental Health Officer).

Unlike the manager of the care home, the Environmental Health Officer's primary concern related to health and safety issues; hence, the rigidity of his interpretation of legislative requirements. Finding the right balance between providing opportunities for people with dementia to be involved in everyday domestic activities and the risks involved in them

doing that clearly influences the social exclusion trajectory; too much unregulated opportunity and a person may not feel (and not be) adequately supported, too little and a person is excluded from the pleasures of risk-taking that the majority of the population enjoy (Lupton, 1999).

Perceptions of risk in relation to people with dementia living in residential care homes are under theorised (Keady, 1996; Marshall, 1999). What is known about risk in relation to this social group and care environment is that perceptions usually derive from technical knowledge bases (usually of the medical and legal profession) rather than from understandings gained by talking to those affected – including relatives and informal carers (Clarke, 2000). This certainly seemed to be the case in the context of this study, as when the Environmental Health Officer was asked whether people living in care home should be allowed to help each other out, his ideas about what should happen in this situation were quite clearly derived from health and safety legislation:

(Residents) shouldn't – most definitely not.... Because (helping each other) is outside their remit... They can put themselves at risk, that is number one. But somebody might be sitting in a chair and they might be seven stone, eight stone, nine stones and this person is not strong enough. They want to help but can they physically help and they put themselves at risk and it is not only that but when you are helping people up and so on, they say you mustn't do it to protect your own health, your back and your limbs and so on and that person might be helping put shoes on, they could injure themselves. They shouldn't help them. Realistically they should be stopped.

(Environmental Health Officer).

This Officer clearly took his professional responsibilities extremely seriously, as in his mind, helping people in a physical way was unequivocally an organisational responsibility, not something that an individual resident should be allowed to do. Moreover, his perceptions of risk were based entirely on legislative framework. The impact of this exclusion from the helping role on at least one participant was to do it when staff were out of sight:

We patients are not supposed to help other patients.

*But you like to help each other out?*

Well if there is nobody about we do, but otherwise you have got to do your own thing.

(Mrs. Wright, age 85 years, Lulworth Court).

Knowing that she was not meant to take responsibility for anybody else appeared to remind this woman of her status as a 'patient'. The resistive behaviour that Mrs. Wright spoke of to seemingly counter this identity is explored in Chapter 10. The connection to make here is between organisational regulations a person's sense of who they are and how they are meant to be – helpless and helped.

While there is clearly great potential for legislation like the Care Standards Act (2000) to promote processes of inclusion, the extent to which it does is a matter for debate. A critical view of an organisation like Carstairs Trust is that what it says happens and what actually happens are two very different things, as 'a language may develop that actually proclaims the opposite of what is going on' (Wolfensberger, 1989: 23). The same might also be said of the two other care homes involved in this study, as both claimed in their respective information leaflets to provide opportunities to pursue individual interests. A possible reason for the gap between what the organisation says happens and what might actually happen is because those on the receiving end of care have very little power compared to those who provide it. As Drake (1996: 52) says 'the helpers invariably occupy positions of power and authority within agencies, and the helped stand in circumstances subordinate to these'. The interpersonal dynamics between members of an organisation are therefore central to understanding how exclusion and inclusion processes manifest.

Social theories of power remind us that some people - because of their position in an organisation - have the 'right to command others, and others have an obligation to obey' (Charon, 1995: 160). Analysis of relations between staff and residents in this study

revealed how power was mediated through the personal routines that made up care home life. For example, when Mr. Smith's key worker was asked what time he liked to get up, it was clear from what she said that she was the one in the position to command and he was the one who had no choice but to obey. She said, 'in the afternoon if he gets his own way. He gets up when I am on, right up and he is in that shower before he knows it'. The no-nonsense attitude of this care worker ensured that not only did Mr. Smith do as he was told rather than what he wanted to do, but also that he was in the 'right place at the right time' – that is, in the shower in the morning, as per routine. The extent to which this care worker sought to exert her will in this situation suggests that 'caring' might sometimes be more to with the power and control than with values of trust and giving (Fox, 1995).

### **8.3 Language use as a reflection of organisational culture**

The role of language in the exclusion of people with disabilities (Marks, 1999a) such as dementia is well recognised (Adams, 1997; Adams, 1998). This section examines the way that language used by participants in this study rendered the situation of people with dementia as hopeless and to create a subgroup of people with dementia for whom social exclusion was even more likely to occur.

Analysis of the language used by participants to describe people with dementia revealed subtle differences in the way that different groups (i.e. care workers, home care managers, relatives and other residents) thought about 'dementia', as both a mental health condition and as a personal experience. Broadly speaking, care workers spoke of dementia - or in the case of written material, portrayed the illness, as an entirely and universally negative experience. For example, both the specialist homes involved in this study used language in their information leaflets which portrayed the condition of dementia in an entirely negative and irremediable light:

'Our staff are experienced in caring for the residents *suffering* from Alzheimer's disease and other forms of dementia'

(my emphasis Brochure, East Wing)

‘the home specialises in taking the active elderly *suffering* from varying forms of memory loss, Alzheimer’s and other dementias

(my emphasis Brochure, Durlston Court)

The portrayal of people with dementia as ‘suffering’ is a powerful one as it suggests the affects of the condition are ‘static and unremitting’ (Bright, 1997: 87). Moreover, it relegates peoples’ experiences to a ‘personal tragedy’ (Oliver, 1996a). Thus, contributing to the cultural construction of impairment as tragic (Marks, 1999a).<sup>31</sup>

It was discussed in section 6.2 of this thesis how prefacing descriptions of people with the word ‘the’ denies difference and diversity within that group of people (Fawcett, 2000). At different times during the focus group with care workers at Encombe House participants referred to ‘the dementia people’ and ‘the demented ones and the ordinary ones’. Although participants did not frequently use these phrases, any reduction of a person to nothing more than their diagnosis is a seriously damaging and dehumanising form of language (Perkins and Repper, 2001: 148). One of the dangers of labelling people with dementia in this way is that they are no longer thought of in terms of a person but rather an illness (Kitwood, 1997). The manager of the East Wing also described some residents in a way that denied their individuality. Not only did she distinguish between those in the ‘early stages’ and those in the ‘advanced stages’ of dementia, she also described some people as if they were no longer a person at all. She said, ‘we have just got this person sitting like a vegetable. They are just withdrawn completely it is frustrating’. The tendency of nursing home staff to orient to people with dementia as bodily matter rather than as people is explored in the literature (Gubrium and Holstein, 1999). In the context of this investigation, because only one of the study sites was a nursing home, the production of this type of language was minimal. Nevertheless, identification of it in a relatively small sample frame suggests a subgroup of people with dementia even more likely to be excluded and marginalised.

The tendency to think of dementia as an entirely negative phenomenon was also evidenced by the way in which some participants expected a person with dementia to behave in a troublesome way. In some instances such comments were made about a particular individual with dementia. For example, Mrs. Green's care-worker spoke of how difficult she could be for some staff, she said, 'I haven't found her very challenging at all...others have found quite a bit of stubbornness with her but I haven't' Similarly, a comment made by Mr. Brown's stepdaughter suggested that care staff expected 'problems' from him. She said, 'Yes. I think they all look after him and they all say he is no trouble'. In other cases, people with dementia in general were spoken of as being potentially troublesome. The manager of the East Wing, for example, said 'inevitably you will get a degree of aggression with dementia' while her counterpart at Encombe House spoke of people with this diagnosis as being a particularly challenging group. She said, 'we are getting more people with dementia. We have coped with most things – you know with people with dementia or Alzheimer's'. The significance of this comment is not that people with dementia need specialist help and support but that the situation of those affected is negatively portrayed. As Adams (1998: 616) explains, 'language is performative and rather than merely communicating what social situations are like plays an important part in their construction'.

The language used in care records is also thought to play a central role in the portrayal of disabled peoples' situation as hopeless and problematic (French, 1993b). In the context of this study, four sets of care records were analysed as part of case study work. This aspect of mapping revealed how usual it was for those who write care records to ascribe the problems that participants had to their impairment (as opposed to the social environment). For example, hyphenated statements in Mr. Smith's case file such as 'might lose his way around the scheme – registered blind' and 'unable to make self cup of tea - registered blind', ensured that any difficulties he might have had remained closely connected to his

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<sup>31</sup> This idea is explored further in section



disabled status (rather than say a lack of signage or staff who could help him). Similarly, in the care records of Mr. Brown, his health status read as a list of ailments: 'partially blind, headaches, muscle cramps. Alzheimer's' with no signs of any plans or guidance, as to what should be from an environmental perspective to help him deal with these. The same interpretation is made of the written assessment made on Mrs. Clarke; this describes her health status as, 'disorientated, dementia and depression' although it is also noted how she is 'sociable' and 'communicates well'. The words that other people use to describe the situation of people with impairment create a kind of action vacuum: others assume nothing can be done because a person's impairment (rather than the environment in which they live) is construed as problematic. As Perkins and Repper (2001: 148) explain, the problem with this is that has the effect of rendering both sides helpless as, 'defining a person as merely a collection of problems and dysfunctions engenders hopelessness in both the person labelled and the one who does the labelling'.

Fieldwork for this study predates modern government initiatives which urge record-keepers in the field of health and social care to write about service users' attributes as well as deficits (DoH, 2002). However, even these policy guidelines do not address the wider issue of language which is disabling because it is based on ideas of 'personal tragedy' (Oliver, 1990). Forms of talk used by some groups involved in this study reflected how common it is to perceive of dementia as tragic and pitiful. For, instance, when Mrs. Van-Houghton of Encombe House was asked about what the other people living in the home were like, she described their situation as being unfortunate (as opposed to oppressive). She said, 'we have got Alzheimer's people and people who have had strokes who can hardly get up and do anything. I feel sorry for them'. Many disability theorists consider expressions of pity towards a person with a disability as fundamental in their wider oppression (Oliver and Barnes, 1998, Morris, 1997, Marks, 2001, Barnes and Mercer, 1996). This is because pity is thought to replace what should be action against the 'real' structural problems that exist in wider society - like, lack of public transport and funding. Evidence of how unhelpful it is simply to articulate pity for someone with impairment was

given when a care worker spoke of why one of the case study participants did not go out very much:

‘He doesn't like going in the garden because he falls. I can totally understand that because he can't see very well. But there is not a lot he can do, he is limited to what he can do because of his eyesight. It is a shame’

(Care-worker, talking about Mr. Smith).

This statement suggested to me that as far as this care worker was concerned, not being able to see was Mr. Smith's problem, not anyone else's, and so his exclusion from the outside world was taken to be an inevitable and irremediable part of being 'disabled'. A slogan used by disability activists during the height of the Disability Movement comes to mind here; 'piss on pity' was what was said, as simply feeling sorry for a person with a disability was considered completely ineffectual in the struggle for human rights (Johnstone, 2001). The fact that Mr. Smith exclaimed 'freedom at last' when we exited the patio doors to conduct our interview on a garden bench, suggested that it was so much that he did not like going out outside, but that he did not like going outside on his own. Therefore, it would seem, that dementia, like any other type of disability is constructed as 'individual misfortune' (Priestley, 1999: 27) and that is partly, it is argued, due to the form of language used to describe it.

#### **8.4 Attitudes towards individuals with dementia**

In the previous section certain forms of language were shown to be influential to understanding meanings of exclusion and inclusion in this context. While words are important, Marks (1999b: 152) suggests that they do need to be understood within the wider social context of 'segregation, exclusion and denigrating practices'. So, as well as analysing what is said about disability, one must also delve into what others feel and think about it; hence, in this section, attitudes towards people with dementia are explored.

MIND (1999: ix) an inclusive society is one which accepts diversity and is not 'threatened by cultures, beliefs or behaviours outside society's norms'. This study investigated exclusion and inclusion processes in the context of residential care and so the 'society' under the microscope in this section is made up of those who visit and who live and work in the study sites; analysis of these peoples' attitudes towards 'dementia' revealed various degrees of acceptance and tolerance. At one end of the spectrum was a very low level of acceptance and tolerance; the married couple living at Encombe House, for example, seemed exceptionally intolerant of some other people in the home. Here, they communicated their annoyance at how other residents seemed to be able to 'get one over on staff':

*Mr Spink* They put too much on these girls. The girls fall for it. And once they have got associated with their worker - with their key - you can't get rid of them. If you say one day will you help me to do so and so well they will come to that person and they will make them take to the toilet and bring them down to dinner and take them upstairs and make them put them to bed and things, you can't stop it you see.

*So it seems that some people like....*

*Mr. Spink* Take advantage of it - that's right.

*Perhaps....*

*Mr. Spink* Where do I go, where I do sit? They know damn well where they sit

(Mr and Mrs. Spink, age 90 and 91 years, Encombe House).

My understanding of their view was that dependency is seen to be a slippery slope, and those who are on it parasites. The couple went on to describe how reliant, and unlike other residents were, from them:

*Mrs. Spink* Like tidying up the table or something like that. They leave it all for the girls.

*Mr. Spink* They even have tea brought up to them. We have never had a cup of tea brought up to us in the evening. But we see the dirty cups left outside for them to collect in the morning. They don't even wash the bloody cups up.

*Mrs. Spink* You know you could carry them down with you couldn't you

(Mr. and Mrs. Spink, age 92 and 90, Encombe House).

The high level of intolerance expressed by Mr. and Mrs. Spink towards people who received more help and support than they did served to make a distinction between themselves and 'others'. Not only did it mean that as a couple they were able to distance themselves from 'non-ordinary people' within the home<sup>32</sup>; but also, and more significantly in a discussion about the impact of cultural influences, by publically labelling certain people within the home as 'deviant', Mr. and Mrs. Spink effectively carved out for themselves a more powerful and superior position within it. In this case the 'power differential' that existed in relation to people with dementia was because one group had the ability to make rules and apply them to the other (Becker, 1963: 17).

The same argument is expounded by Faulkes (2000: 29) who suggests that a 'cultural exclusion' can occur whereby one group of people can be perceived by others as 'outsiders' or second class citizens by the dominant population. While Mr. and Mrs. Spink did not refer directly to people with dementia, other exhibitions of intolerance were clearly directed towards people with mental health problems. The following participant, for example, made it quite clear whom she did not wish to socialise with:

You have got to be friends with everybody. Whether you like them or not. I don't mind that but this idea of people coming in here, their minds have gone, or they are a bit dopey. It annoys me. Because why should I be mixing with that

(Mrs. Wright, age 80, Lulworth Court).

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<sup>32</sup> This idea is explored in Chapter 9

Not wanting to mix with people who do not seem very able minded might be a strategy for maintaining one's own sense of identity<sup>33</sup>. Even so, Mrs. Wright's annoyance at having to mix with people whom she saw as very different from her revealed how damaging intolerance can be to the identity of someone affected by dementia: loss of identity as a friend or confidant. Other older people who took part in this study expressed equally strong views about the inadequacy of people with dementia. For example, when asked if there was one thing she could change about living where she was, one participant replied, 'that there would be decent people that comes in here. And were sensible'. Mr. Green, the husband of one of the case study participants was equally patronising towards both his wife and the other women she lived with. He said at one point, 'when (my wife) first went to Durlston Court she referred to them all as dotty women but she doesn't now because she is one herself. The 'invalidation' of people with dementia in this way is seen as a sign of a malignant social psychology (Kitwood, 1990).

Other comments by Mr. Green reveal the extent to which he contributed to the marginalisation of his wife's identity by this means. Having cared for his own wife, Mr. Green identified more readily with care staff rather than those who were living in a care home; hence, his story line involved supporting the work of care staff and belittling the rights and needs of people with dementia:

'I do admire those girls at Durlston Court because it must be terribly distressing with the pressure and all that; sometimes when you go there, there are three or four of them all demanding something or all doing something silly you know, and then there is all this business of wanting to go home

(Mrs. Green's husband, Durlston Court).

As is the case with people with learning difficulties, the thoughts, feelings and experiences of people with dementia are trivialised and maligned because attention is paid to the problems a person creates rather than to the difficulties they experience (Marks, 2001:

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<sup>33</sup> This idea is explored in Chapter 9.

617). Although Mr Green went onto acknowledge the importance of treating people with dementia as human beings, he did so in a way that immediately marginalised their collective status. He said, 'they must be respected as individuals although they are old and ga-ga'. Mr. Green was clearly reluctant to accept that people with dementia were adults deserving of the same respect as anybody else. The tone of 'infantilism' in the narratives of Mr. Green is further evidence of the presence of a malign social psychology existing (Kitwood, 1990).

While Mr. Green clearly found it difficult to accept his wife's mental health problems, staff within the home were much more tolerant. The following description of Mrs. Green by the manager reveals a significantly greater readiness to help and support someone with cognitive impairment:

She is very much her own person in a way. She is still in charge of herself and her life as far as she sees it. And to be told by another resident – she I think would put herself more with the staff and she finds it intolerable. She was a very witty lady and a very intelligent lady, and she still has that kind of wit and sometimes she can be – it comes out in a rather rude manner – and somebody can take offense at what she says – but it is part of her witticism that does not always come out appropriately now. And of course the staff can understand this but other residents can't

(Manager of Durlston Court).

The manager draws on what she knows about Mrs. Green's biography to help her and her staff understand this woman's behaviour. The difficulty she (or rather Mrs. Green) faces is that other residents are unable to do this; neither it would seem is the husband. Researching levels of tolerance and acceptance, from the basis of Kitwood's position, demonstrates that 'malignant' social events, like exclusionary processes are not isolatable to one single setting, as different individuals have different views towards mental health.

So far, those most intolerant of people with dementia have been older people. This resonates with the findings of a recent large-scale survey of public attitudes to mental health. In that survey respondents most likely to express intolerant attitudes towards people with mental health problems were older people – respondents aged sixty-five years and over (Scottish Executive, 2002). Although the authors of this study did not speculate on why this might be the case, it might be, as Turner (1989) suggests that older people are in ‘competition with other social groups because the negative experience of ageing results in them being denied’ (Higgs, 1997). In the following example of intolerance toward a person with dementia, it might be negative experiences of caring (as well as ageing) which are to blame; here Mr. Green describes how his wife reacted when she first moved into the home:

You see the first few weeks – few months there it was always an awful business when I went to see her on leaving she would start to scream you are leaving me, you are dumping me, we might as well be divorced and all this sort of thing and you don't want me any more and why can't I come home and all this sort of thing and now she has got beyond that, the stuffing has gone out of her to the extent that she is now much more phlegmatic than she was

(Mrs. Green's husband).

Mr. Green seemed to explain away his wife's pain and anguish by seeing it as part of the temporal order of dementia – ‘she has got beyond that’ – however, if one takes away the ‘dementia factor’ for a moment, Mrs. Green's comment about divorce would seem quite legitimate given the circumstances: her husband had removed her from the family home and was no longer prepared to care for her. The point is, where does a woman like Mrs. Green take her pain? She is hurt and angry by the actions of her husband, but to whom can she turn for a complete understanding of her experience (Ussher, 1991: 203). The tendency of others to trivialise and patronise the expressive behaviour of women, is a factor in their exclusion from any form of support or remedying of their unhappiness. This perhaps explains why one woman responded to me in the way that she did when I spoke about her

being upset. She said, 'I am not upset, I am emotional'<sup>34</sup>. Emotions are an important mode of communication by which people can impart how they feel within and about a relationship (Burkitt, 1997).

The emotional experience of impairment is important to note, as it is often this which non-disabled people overlook or underestimate when they consider the barriers facing a person with impairment (Marks, 2001). Mrs. Windsor, age 75 years, of Lulworth Court was asked how she was feeling that day, her response indicated that although she had people she could confide in about her feelings she did not want to. She said, 'oh I get depressed occasionally but I don't worry (my family). I encouraged her to elaborate on her feelings, 'I don't know what it is – I don't know. I can't express myself'. This woman did not seem to have the language to describe (or was not prepared to talk to me) about the emotional discomfort she was in. Similarly, Mr. Smith's care worker did not seem to think he was too troubled by this aspect of his health. She said, 'It is not so much his memory because he doesn't know he has got memory lapses'. Similarly, when Mr. Brown's key worker was asked to say what Mr. Brown was like generally, her reply assumed his experience of everyday life was relatively carefree. She said, 'the only thing he does worry about out is he likes to be shaves – *he is quite fussy about his shave every day*'.

I think it is reasonable to argue that these accounts were not rooted in an accurate understanding of the experience of impairment (Marks, 2001: 41). For example, according to Bendelow (2000: 107) the belief that 'all men do is shave' is a gendered one as it does not take seriously the pain and anguish that men experience. Given that this study draws from such a small sample frame of men (and women) it is not possible to analyse further about gender differences. However, what is arguable is that despite the emotional angst that many participants in this study seemed to be experiencing at times, they, like many other people with dementia, had few if any opportunities for psychological support

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<sup>34</sup> I met this woman during the early stages of the study to ask her if she would be interested in taking part, she cried almost the entire time we were talking, partly because she was very unhappy about the care home



(Bender and Cheston, 1997; Burns, Denning and Baldwin, 2001; Procter, 2001; Clare, 2002).

Other studies that have investigated relationships between older people living in residential care homes have found that what individuals find most difficult to tolerate is certain behaviours of some people who are confused. Meacher (1972) identified 'physical restlessness' and 'interference with others' possessions' as behaviors people find particularly difficult to accept, both of which were referred to as problematic by one of the managers who took part in this study:

We are aware people are apt to wander but often they don't touch anything but sometimes the residents whose room it is aren't always so tolerant and not always understanding – but most of the time they don't touch anything

(Manager of Encombe House).

Lack of tolerance towards people who break societal norms about personal privacy would seem to be a long-standing barrier to inclusion within the residential care sector. From a sociological perspective, knowing what is appropriate and acceptable in terms of how to act, talk and dress, provides the orientation we need to help us fit into the groups to which we belong (Bauman and May, 2001). As dementia is a condition that impacts the cerebral lobes - a structure of the brain which controls (amongst other things) moral behavior (Herbert and Thomson, 1997) - people affected are quite likely to break the codes of conduct that exist within a society because they no longer 'know' them. In the context of this study, this proved to be one of the single strongest influences in the exclusion of people with dementia; here, the manager of Lulworth Court explained why:

We recently had a person who in the lounge area who kept stripping off. The trouble is if they do not accept that – if it goes on too long – even when the person is not stripping off they will isolate her, they won't want to sit by her at lunch time and this sort of thing

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she was living in; it was decided she was not well enough to participate in the study.

(Manager, Lulworth Court).

This woman – who was probably cognitively impaired - was shunned by those she lived with because of her lack of sexual inhibition. Given that the decision to move someone with dementia into a residential care home usually arises when their behaviour cannot be managed where they are (Audit Commission, 2000: 66) it is salutary to note how certain behaviors have always seemed to be difficult for people living in residential care homes to deal with.

At the start of this chapter it was suggested that an inclusive society is one which is able to accept behaviours outside society's norms'. The Carstairs Trust Homes sought to raise peoples' awareness of the possibility that some peoples' behaviour may be unusual by stating in its Residents Charter how, 'living in any communal environment means having to make some allowance for the needs of others'. There was some evidence that this directive led to more tolerant attitudes amongst residents. For example, the following participant seemed to accept that she and others had little choice but to tolerate the eating habits of another resident:

On our table there is a man - and he is a very messy eater and you know he gets it all down him, and he coughs and he splutters and it really puts you off. But you can't say anything....

*What stops you from saying something?*

Well it is a bit hard on him... I suppose someone has got to have him, but unfortunately it is us... Well when he starts coughing and spluttering we three ladies we sort of look up at the ceiling and then look over there and then look at him and then ... thank god he doesn't do it too much.

(Mrs. Kitchin, age 76, Encombe House)

My interpretation of this was that these women put up with sitting next to this man, albeit reluctantly, because they realised a residential care setting requires comprise (Atkinson,

1998). Similarly, after telling the story of how residents responded to the woman who took her clothes off in public, the manager said how understanding people usually were of those with dementia, although there was one thing, seemingly unrelated to mental health problems that he said people were not prepared to tolerate:

By and large the majority of residents without dementia here are very tolerant – they are very tolerant.

*What are they sort of tolerant of?*

They will tolerate in that they can help somebody, if they help somebody it encourages somebody. When we do ceramics classes they are very supportive of people who are finding it difficult because they can't remember or whatever, they will not tolerate bad language, I certainly picked that up very quickly, they will not tolerate bad language or particular males who are I suppose chauvinistic I suppose

(Manager, Lulworth Court).

Different behaviours would seem to evoke different levels of tolerance. Indeed, the prospect of having to mix with 'uncongenial others' in one of the main factors that puts older people off residential care (Biggs. 1993: 149)

Milder forms of intolerance were detected in other narratives. For example, Mr. Smith's son sounded somewhat perturbed that his father readily recalled the past but appeared to show no interest in more recent events:

Funny enough long-term stuff it is quite amazing when he was in the RAF years ago and he would remember things that happened donkey years ago, but he wouldn't remember to ask how the kids were

(Mr. Smith's son).

Mr. Smith's son sounded to me as if he found the effects of his father's impairment annoying as it meant he did not behave in the way that he thought a grandfather should behave – that is, by asking how his grandsons are. Some participants in a study by Reed

(1999) were annoyed by the conversational abilities of residents who were confused, and so kept a distance from them. Mrs. James of Purbeck Lodge, aired a similar attitude when she spoke about other people in the home, she said, 'I find that the conversation is very difficult (with people in the lounge). I have tried to work at a conversation with some people and you don't get it'. Similarly, Mrs. Housel of Encombe House, while quite understanding of people with mental health problems, did not seem inclined to get too close to 'them'. She said, 'unfortunately there are not many here that are able to have a reasonable conversation with. Lots of them are demented and some of it is Alzheimer's I think'. The main conclusion to be drawn from this discussion is that whatever people feel about 'mental health' and however tolerant they are of people affected, exclusionary processes in the form of isolation and discrimination are likely to be triggered by someone at some stage.

## **8.5 Summary**

This chapter has discussed the power that some people in organisations have to exclude others. Each section focused on a different aspect of this relational dynamic. In the first section, the focus was on the power of those who ardently interpret health and safety regulations and routine to exclude people from everyday roles and choices. The positive influence of understanding and 'best practice' initiatives was highlighted here. This led to a discussion about how influential language is in the exclusion of people with dementia. The key interpretation of this data is that, expressions of hopelessness and pity are triggers in themselves to exclusion, as people seemed to have made little attempt to understand a person's behaviour in the context of the social situation (Bond, 1992)

Finally, the chapter concentrated on a relatively unexplored aspect of social exclusion in this context, that of, the cultural exclusion of older people with dementia by other older people. Observations made in this section resonate with the few findings that there are in relation to this issue and that is that a person with dementia is likely to be ostracised as and when their behaviour does not concord with other peoples (Meacher, 1972; Reed, 1997).

People in this study seemed to find it particularly difficult to tolerate those who did not communicate or who behaved in what they perceived to be a socially unacceptable way.

## **CHAPTER NINE**

### **The impact of health status on meanings of exclusion and inclusion**

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#### **9.1 Introduction**

This chapter directly addresses the third of the subsidiary research questions about the way health status influences meanings of exclusion and inclusion. Discussion focuses on how poor health contributes to meanings by limiting the capacity of individuals to take part in mainstream activities and events (Moran and Simpkin, 2001). The three main areas of health under discussion are dementia, physical impairment, and normal biological aspects of the ageing process.

It was revealed in Chapter Three how any focus of impairment is seen by some to undermine a social model of disability. In this chapter it is argued that analysis of peoples' experiences of impairment and of getting older is vital for understanding the full range of barriers that the people with dementia who took part in this study faced.

#### **8.2 The impact of dementia**

The global and progressive impact that dementia has on the brain was described in section 2.3.1 of this thesis. The point was made in that section that as so much is known about the neurological as opposed to the personal impact of dementia, social researchers in the field increasingly seek to understand the subjective experiences of living with this condition (Keady, 1996; Gillies, 1997, Lyman, 1998, 2000; Bender and Cheston, 1997; Rundqvist and Severinsson, 1999; Barnett, 2000; Martin and Younger, 2000; Proctor, 2001; Reid, Ryan and Enderby, 2001; Phinney, 2002). The purpose of this section is to use this developing area of knowledge as a guide to focus and strengthen analysis of how the condition shapes meanings of exclusion and inclusion for the small group of older people with dementia involved in this study.

People with dementia commonly experience two main types of symptom; these are described as 'cognitive' features (such as memory loss and language disturbance) and

‘non-cognitive’ features (such as personality change, depression and wandering) (Alzheimer’s Disease International (1999b)). This section draws on data collected from this study to show how the emotional experience of being impaired in this way compounds incapacity by fostering feelings of nervousness and self-doubt.

Because dementia causes atrophy of the cerebral lobes those affected have significant and progressive problems with memory (Herbert and Thomson, 1997). The diminishing capacity to remember is a strong influence in the exclusion of people with dementia as it means a person has less and less knowledge to draw upon and make sense of the social world and their place within it. As Killick and Allan (2001:114) explain, being able to recall ‘information, events and experiences provides an important sense of mastery and power’. A simple example of how poor memory delimits a person’s capacity to know what is going on and thereby feel in control of their life was given when one of the case study participants spoke of the amount of telephone contact she had had with her daughter:

*Interviewer - Do you speak to (your daughter) on the phone?*

Yes, but she hasn't rung up now for about three weeks. I don't know what has happened.

*Care worker- She phoned you up last week.*

Last week was it. I don't know I don't remember my duck. Are you sure it was last week. Oh well I can't grumble then if she rang last week can I. that has filled the hole up. I can't remember she did though

(Mrs. Clarke, Lulworth Court, age 80 years).

Having no recollection of the most recent phone call with her daughter (which the carer involved in this interview reminded her of) Mrs. Clarke revealed how important memory is for resolving feelings of doubt and insecurity.

According to Giddens (1991) a sense of security is engendered by awareness and enactment of familiar habits and routines. Mapping other participants’ accounts of memory loss, it was clear how troubled some individuals were by not being able to remember what

they had done from one day to the next. Take for example a comment made by one woman:

The thing that does worry me is that my memory is going. And I just cannot remember what I did yesterday or what I did before. And that is a worry.

*Have you spoken to anyone about it?*

I don't think so, I long time ago I may have done

(Mrs. Peters, age 87 years, Durlston Court).

Mrs. Peters seemed to me to be concerned about her diminishing capacity to remember what she had done the day before; moreover, the vague recollection that she had spoken to someone about her poor memory in the past appeared to compound her sense of anxiety about it. Many of the informal exchanges I had with Mrs. Dryden were taken up with her asking me questions about what she should be doing and where she should be, seemingly unaware of any routine activity that she might otherwise be engaged in. Indeed, the high state of anxiety that Mrs. Dryden appeared - and was reported by care staff - to be constantly in was why the more formal interview with this participant was only ten minutes in duration. Anxiety is common amongst people with some insight into this type of impairment (Woods, 2001). Mrs. Dryden certainly seemed to have some insight into her condition as she often asked me, 'do you think it is Alzheimer's, that I've got?' In this study, anxiety was clearly a contributory factor in social exclusion as without the memory skills to help reduce these feelings, a person – like Mrs. Dryden – was in danger of becoming completely incapacitated by the relentless psychological and behavioral disorder it created. The 'ontological security' that Giddens (1991: 35) refers to and sees as crucial for the healthy maintenance of self identity, would seem therefore, to be extremely difficult to attain for someone affected by cognitive impairment.

Because experiences of the body can often be unpleasant and overwhelming for a person with impairment some disability theorists argue for more analysis of disabled peoples' experiences (Crow, 1996; Corker, 1999; Marks, 2001). In this study, it was only when participants' embodied experiences of impairment were mapped out that another barrier to



inclusion was revealed. Take for example the following comment made by Mr. Brown after I asked him how his memory was now that he was getting older; his reply revealed how a poor memory made it extremely difficult for him to participate in one of the most basic forms of human activity - talking:

Poor, at the moment I can't remember anything, well it has gone. You sit talking to me like this and if I went out there and came back again I shouldn't be able to remember what you said.

*What is that like not being able to remember something?*

More of a torment I think. Still you have got to get past that haven't you... That is the thing that gets me I start talking like this and then it goes out of my head. I have a hell of a job to get it back.

*And what is that like not being able to remember things?*

It is awful really, yes.

(Mr. Brown, age 84 years, East Wing).

Mr. Brown's capacity to enjoy the pleasures of social interaction was limited as he had trouble remembering the conversations he had with people. Similarly, Mr. Smith described at one point how exasperating he (and his family) found it because his mind would no longer function in the way that it should:

Well my boys can't understand it, sometimes I can't remember what happened yesterday, but I remember years ago.

*Why do you think that is?*

I don't know. I honestly don't know. And when I was working my memory was good. But I don't know this last six months I don't remember sometimes what happened yesterday. But I remember weeks ago. I wonder why. My brain works backwards. It has made me so nervous. My memory has gone terrible. Well I will use the word again it's frustrating. Oh dear, oh dear

(Mr. Smith, age 77 years, Encombe House).

Having been a productive and healthy man, Mr. Smith sounded irritated by the memory loss he was experiencing. Moreover, like Mrs. Dryden, he felt nervous and perplexed because of it. The importance of noting the emotional experience of impairment was

discussed in section 8.5. of this thesis. Highlighting it again here reveals how much a daily problem memory loss is for a person with dementia – not least because others do not recognise it is as such. The experience of ‘losing knowledge of what is happening in the world’ is reported in another study (Phinney, 2001: 52) suggesting this might be a significant biological influence shaping meanings of exclusion.

Dementia also affects a person’s ability to speak (Adams, 1997). The ability to communicate is central for social inclusion, as the opportunity to engage in social interaction provides, amongst other things, a powerful means of preserving identity (Whitworth, Perkins and Lesser, 1992; Killick and Allen, 2001). Mr. Smith conveyed the important role that language plays in his life when he emphasised how much he valued being able to socialise with others. He said, ‘thank God I can communicate and make friends easy’ and, ‘if you talk to (other people) about anything really you get on all right’. The fear of losing the ability to speak through a lack of practice may explain why social relations were so important to Mr. Smith (Herbert and Thomson, 1997). As someone with a vascular type dementia, Mr. Smith was apt to communicating in a way that clinicians might describe as slow and monotonous in tone (Muir, Baseby, Cavaglieri, 1997). In other words, he had a tendency to repeat the same words and phrases and not be able to introduce linguistic variety (such as metaphor) into his conversation. As his son said, ‘he keeps repeating things in the short term’ and ‘he talks all the time about his time in the RAF, but he won’t remember to ask how the kids are’. A poor memory and diminishing communicative abilities meant that Mr. Smith was inclined to repeat himself, much to the annoyance of others it would seem; here his care worker explained how frustrated she sometimes got with this aspect of his behaviour:

He is a nice fellow usually, but I mean you can stop have a conversation with him he asks you about your family and then two minutes later he will say how is the family love?

*What you sort of have the same conversation with him again?*

The whole time. I say they are fine. It is no good saying you have just said that to me, because that would get him in a mess - but fine, fine, two minutes later again, how is the family love. The same thing, over and over, until you break that routine of saying that and he will go on to something else.

*And is that what you try and sort of do.*

He just repeats himself over and over again if you don't. I let him do it a couple of times and change the subject.

(care worker at Encombe House, talking about Mr. Smith).

Repetitive statements and continually asking the same questions is a common difficulty for someone affected by dementia (Killick and Allan, 2001). In the case of Mr. Smith it is possible to see how it shaped meanings of exclusion by limiting his capacity to interest his key worker and son, and to engage in a conversation that would not alienate him from them.

No two people with dementia will experience the condition in quite same way, as cognitive impairments, as with disabilities in general are highly heterogenic (Butler and Bowlby, 1995: 16). Certainly the language skills of people taking part in this study were very different. For example, Mr. Brown was less repetitive in what he said than Mr. Smith, and he seemed more able to engage in normal conversational patterns such as 'turn taking'. The best example of his ability to take part in a conversation was when, after we had been talking about the general routine of the home and how he liked to spend his time, I rather *unskillfully* asked if there were anything else he liked to do in private. He responded to this with a wry smile and asked, 'what are you thinking of - you can't think of anything can you?' He knew what I knew that the question I asked him was absurd. Mr. Brown then went aptly on to change the subject and to talk about gardening. Unlike Mr. Smith, Mr. Brown had the ability to recognise conversational breakdown and to deploy strategies to repair it (Muir, Baseby, Cavaglieri, 1997).

Mrs. Green had different abilities again. Concerns were expressed in relation to this participant about the progressive reduction in her language skills; here the manager describes how increasingly difficult Mrs. Green was finding it to engage in an activity she clearly enjoyed doing:

(Mrs. Green) does like poetry – we have a good poetry group and she joins in with that. But just lately I have noticed that she has not bothered to read and although she says she cannot see it, I am not sure that it is actually her eyesight but that that is an excuse because she is tripping over the words and not as good and I think the thing with [...] just lately I have not asked her to read so much and asked other people and she enjoys listening

(Manager of Durlston Court)

Disturbance in reading and writing is particularly common in Alzheimer's type dementia; however, as the ability to read aloud remains well preserved it might be that Mrs. Green was actually having more trouble in comprehending rather than reading what was written (Muir, Baseby, Cavaglieri, 1997: 294). Having been the owner/manager of a bookshop, taking part in an oral activity like poetry reading was probably something that Mrs. Green was once able to do with ease and skill. However, another person might have found this activity difficult even before the onset of dementia. This is because as, Moran and Simpkin (2001:5) note, poor health status might be a consequence of broader patterns of social exclusion, in education for example. A comment made by Mr. Brown highlighted this possibility, he said, 'Oh I don't know. I can talk about anything really. Well I am not a very educated man. I only went to the village school'. Arguably, the exclusionary processes resulting from a lack of cognitive capacity might have affected a person with dementia all their life.

According to Killick and Allan (2001: 71) 'the propensity to tell stories to ourselves and others is basic to how we develop and maintain a sense of identity – how we know who we are and we fit in to our social and physical world'. In the context of this study, it was clear from the difference in appearance and length of transcripts that participants with dementia were less able to 'construct stories' in the way that interviewees are said to do (Ritchie and Lewis, 2001). The majority of interviews with older participants and relatives produced pages of (sometimes uninterrupted) dialogue; however, this was not usually the case with a transcript from an interview involving a participant with dementia. For example, the interview with Mrs. Windsor produced a disjointed narrative, as she tended to answer questions with short simple statements like this:

You used to live up north didn't you

Well not so much north. I can't remember now

*What sort of things do you like to eat?*

To eat, I will eat anything

*Is there anything you would like to ask me about?*

No, not really.

*What do you do during the day?*

Well sometimes I am doing things but otherwise I just go down and have a sleep in the afternoon.

(Mrs. Windsor, age 75 years, Lulworth Court)

A combination of poor language, memory, and interview questions prevented Mrs. Windsor from being able to talk at length about her background and everyday events. Similarly, Mrs. Dunn who was 91 years old fondly referred to her two sisters throughout the interview; however, she never spoke about them or indeed any other aspect of her life in any great detail, instead her conversation was characterised by a series of short statements such as, 'I have forgotten (where my sisters live). Probably not far away, which is nice of course'. Unlike many of their counterparts in the second sample group, these two women seemed bereft of what to say and how to expand on responses. While it is common to reflect upon the fragments of data produced by people with dementia, this is often done as part of a wider discussion about methodology (Mills, 1997; Killick, 1998; Gillies, 2000, Procter, 2001). The findings of this study underline how severely cognitive impairment limits the capacity of people to take part in a basic human activity – talking.

### **9.3 The impact of physical impairment**

Given that the mean age of the sample group of older people with dementia was seventy-nine years, a high prevalence of physical (as well as mental) health problems was found. The co-morbidity of health problems amongst older people is noted in the literature. Of the four case study participants for whom data about health status was sought, it was noted that, both men were visually impaired; in addition, Mr. Smith had had a stroke; Mrs. Green

wore spectacles and had breast cancer; no physical health problems were recorded for Mrs. Clarke.

It is estimated that 97% of people aged sixty-five years and over have difficulty with eyesight (Briggs, 1993). Given the extraordinarily high prevalence of this impairment it is surprising that so little is known about its impact on an older person's capacity to socially engage in social interaction. Of course not everyone who is visually impaired is necessarily disabled by it, as wearing spectacles remedies the problem completely for the large majority of older people (ibid.). A person with dementia might however forget they need to wear glasses or forget where there are glasses are and so visual impairment becomes a problem for someone when it need not necessarily be. The potential of this happening was highlighted when the interviewer asked Mrs. Green if she would care to look at the information leaflet about the project:

*Have you got your glasses?*

Yes

*Can you have a little look?*

Is this to draw out some character in me or is to find out what is to be written about?

*It is to find out what you like to do*

Where are you from?

(Mrs. Green puts on her glasses)

*Is that better?*

Yes slightly

(Mrs. Green, Durlston Court)

Mrs. Green wore spectacles to help her read, even when prompted to wear them though, her ability to see words was only marginally improved. Due to the catastrophic nature of a disease like dementia, difficulties with eyesight may seem diminutive or less relevant. However, this may not be how impairments are experienced by those they affect.

According to French (1993:16) – who incidentally describes herself as a ‘visually impaired person’ – a major impact of not being able to see fully is not always to recognise people or to read non-verbal cues correctly. Indeed, I observed whenever I visited Encombe House that unless I went up very close to Mr. Smith and said hello and reintroduced myself, he would not have seen me pass by and known I was there. Clearly the potential for ‘missing out’ on opportunities to socially interact is there for someone who has very severe and intractable problems with their eyesight. The frustration of not being able to see very well was a recurrent theme of Mr. Smith’s interviews. He described at one point what it was like when he first started to lose his sight, he said, ‘I couldn’t believe it was happening to me. Really I couldn’t’. At another, he expressed how much better he thought things would be if his eyesight were to improve, ‘I wish I could see better that is all’ and ‘if I could see properly you know’. Unfortunately, as Mr. Smith explained, the scope for treatment is very limited and so he felt had no choice but to put up with the social and emotional pressures that it creates:

No, no. I am fine. It is only my eyesight and so on. It is frustrating like I told you, you know. But I try to keep as happy as I can you know, I mean you can’t do anything about it can you. Unless they can do something, but they can’t. I have been told I have got to live with it

(Mr. Smith, age 77, Encombe House).

As emotionally testing as it is there is very little that can be done to treat some causes of visual impairment (Briggs, 1998).

The diminishing ability to engage in activities involving close eye work was a recurrent theme in the data. This is how these three women with dementia responded to a question about the sorts of things they enjoyed doing:

Sewing, making curtains. That’s what I used to do. But I don’t do that now

(Mrs. Dryden, age 85 years, Encombe House).

Reading chiefly. Listen to music. I used to do embroidery, but I don’t do that much no. Sewing, writing letters. Nothing else really

(Mrs. Peters, age 85 years, Durlston Court).

Yes I used to love (books), but I can't see too well now, so I can't do it so long as I used to. But I have done a lot in my life

(Mrs. Clarke, age 80 years, Lulworth Court).

Other than Mrs. Clarke who said about not being able to see very well, it was not clear from their accounts why these women were no longer able to do the things that once they enjoyed doing. One might reasonably suppose that it was due to a combination of factors, including poor health status such as visual and cognitive impairment. Whatever the cause(s), no longer being able to engage in an activity that had been central to one's life, means that a person's opportunities for self-expression are limited. This is most clearly evidenced by the response that another participant gave to the same question:

I used to knit, knit, knit. All my life. All the grandchildren all had knitted clothes and new baby clothes and all that...Now I can't knit now because of this hand. I can't hold a knitting needle and I can't see the patterns

(Mrs. Layder, 80 years, Lulworth Court).

My interpretation of this was that knitting was for this woman a way of being a wife and grandmother. Unfortunately an arthritic hand and poor eyesight prevented her from expressing herself in this way anymore.

#### **9.4 The impact of age and the ageing process**

Unlike mental and physical ill health, age is universal – it happens to everybody (Bond, Briggs and Coleman, 1993). This means to say that age in itself is not necessarily a causative factor in social exclusion; however, in the context of this study the biological aspects of ageing did seem to compound some individuals' inability to take part in everyday life.

The biological process of ageing is characterised by a 'general decline in physiological effectiveness' (Briggs, 1993: 54). Changes to key bodily organs such as the heart, lungs and kidneys make the ageing body a problematic one: often causing pain and infirmity and other signs of mortality (Tulle-Winton, 2000: 64). The day-to-day toil of living through the



ageing process was alluded to by one of the case study participants after she was asked if there was anything that she worried about:

Only how tired I feel, I haven't been too well. You don't feel like pushing and pulling about when you don't have to do you.

*Why haven't you been too well?*

I don't know, it is age I expect. I am getting old you know.

*When you say you don't feel well, in what sort of way?*

Well it is your system isn't it, I can't explain what it is; you must know what it is.

*Do you feel tired?*

Yes, I do very tired. I am just as tired when I get up as when I have gone to bed. That is the truth. I need a tonic or something, but they don't give me one. They used to years ago, the doctor used to mix you up a good tonic. You can't get nothing now.

(Mrs. Clarke, age, 80 Durlston Court).

It seemed to me that For Mrs. Clarke, there was little relief from the ageing process.

Another participant who also referred to the general experience of growing older described how the process left her feeling:

'I wake up in this sort of compost state. I am very tired...I am very tired, I am 85, and I get terribly tired, I just can't be bothered....I get very tired. Of course I should do at my age

(Mrs. Peters, age 85 years, Durlston Court).

Social theories of ageing offer ways of understanding how people manage biological decline (Coleman, 1993). For example, from the perspective of Erikson (1965) Mrs. Clarke and Mrs. Peters would be described as going through a psychological conflict of integrity vs. despair – that is, as older people they are both at a stage when they need to work out for themselves how fulfilling their life has been. However, the problem with this perspective, is that it assumes the psychological stages that people go through are linear. For it might be that, as retired working women, Mrs. Clarke and Mrs. Wright are actually going through a

conflict of industry vs. inferiority<sup>35</sup>: they want to be productive but their ageing bodies do not allow it. The possibility of this is highlighted most clearly by a comment made by one of the eldest people to take part in this study:

I am bored. I think I should do something...I wonder if I can do anything, but I don't know if there is anything I can do. I would if I could but the trouble is I get this giddiness. I am not an ill woman but this awful dizziness, I don't think I can get involved and do something without letting people down. I was a Girl Guide and a Brown Owl...that is something I would like to be

(Mrs. Cheney, age 90 years, Purbeck Lodge).

While Mrs. Cheney did not see herself as a 'sick person' she considered her health to be too unstable and unpredictable to let her do the sort of active things that she wanted to do. The biological reality of the ageing process clearly impacts on peoples' ability to participate in everyday life.

As well as general decline, the normal ageing process also leads to specific changes in body functioning. For example, reduced efficiency of the lungs, and weakness of the chest muscles makes breathing more difficult, particularly on exercise, for an older person (Briggs, 1993). This too, can have a major impact on a person's ability to take part in everyday life. For example, shortness of breath meant that one participant was unable to hold a conversation as well as she liked:

I am a bit out of breath talking.

*We can take it slowly. Is there anything else that worries you?*

Just when I get out of bed but nobody seems worried about it, I told this doctor but he doesn't seem to be worried about it...Any extra effort makes me lose my breath, so you see what I mean.

*Do you want to stop now?*

No I can't do anything about that can I?..You see I am puffing now, why I am puffing. Why is that, tell me that.

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<sup>35</sup> According to Erikson (1965) people go through this stage as a child just before adolescence.

*Does it happen a lot does it?*

Oh yes, any extra effort makes me puff.

*You must find that difficult.*

It is difficult yes. And people comment on it

(Mrs. Peters, 85 years, Lulworth Court).

This woman with dementia was aware of her inability to hold a conversation without getting out of breath. Mobility and difficulties associated with accessing information (such as shortness of breath) are critical influences in the capacity to claim one's rights (Smith, 1997). It would seem that normal biological processes of ageing place older people in a very weak position in this respect.

The ageing process also leads to considerable changes in a person's mobility and general fitness levels (Herbert and Thomson, 1997). Changes of this nature help explain the increased risk and incidence of falls amongst older people (Le May, 1997). The high prevalence of falling amongst this age group was reflected in data collected for this study; of the twenty-four older people who took part, twelve spoke of falling, either as a contributory factor to the admission to the care home, and or because it was something that they feared would happen to them. This aspect of the ageing process contributed quite clearly to exclusionary processes by leading people to be fearful of moving; this is how one participant responded to a question about whether she liked to go out into the garden:

No, Not on my own, No I can't.

*Why are you not able to go out on your own?*

I am just not steady...I have lost my balance.

*So have you fallen in the past have you walking outside?*

No. I haven't been out there.

*You have never been out round the garden?*

No

*Is that because you have never wanted to?*

Mainly because I am too scared to do it in case I fall.

*And what do you think would help you to overcome that feeling of?*

To stop myself from wobbling.

(Mrs. Kitchin, age 76 years, Encombe House).

It would seem that difficulties in keeping her balance meant that this woman was reluctant to go outside on her own. One of the case study participants also described how fearful she was of falling, although in this instance, it was not so much the fear of falling that abated movement but fear of the upset that it might provoke:

I was told not to go down (for breakfast) on my own because I might have fell down and so she was ages fetching me this morning that is why I was late coming in to breakfast. I thought I must get out there, if I fall down I shall be into trouble. I ought to wait. I think she forgot all about me, perhaps she had other things to do.

(Mrs. Clarke, Durlston Court).

A combination of poor health status and wider organisational factors (such as lack of staff) meant that Mrs. Clarke was limited to when and how she could leave her room to join other people.

As well as physical changes, the normal biological process of ageing can also affect a person psychologically (Biggs, 1993). For example, the tension between how society expects an older person to be and how that older person feels about themselves was discussed in section 2.4 of this thesis. In the context of this study, that tension was revealed in the way that several participants seemed to have internalised oppressive messages about 'growing old'. Internalised oppression has been described as a psychosocial process whereby people turn social categories 'into weapons with which to injure (their) selves, every day of (their) lives' (Mason, 1992, quoted in Marks, 2000: 69). While the expression has been used to explain how and why a person with a disability might devalue himself or

herself, it has yet been used to help analyse the way that older people describe themselves. Consequently, it was significant when in the process of indexing and charting data for this study a self-injurious narrative was found in relation to the social category of 'old'. In fact, almost half of all (older) participants referred to themselves as 'old', and with the exception of one, did so in a way that suggested that they held a very low opinion of themselves and or what they might expect out of life as a result. A participant from the first sample group, for example, defined herself as old in a particularly self-deprecating way:

I am a member of the old age you know. I don't feel like it.

*You feel younger?*

As long as I don't look in the mirror. You are very kind putting up with my ugly age. I am an old woman

(Mrs. Dorking, aged 87, Durlston Court).

By saying how she belonged to 'the old age', as if it was indeed a separate and definable social group, Mrs. Dorking effectively defined herself almost entirely by her age. That is to say, like many ageing women, Mrs. Dorking was concerned about changes to her self-image and physical appearance (Bernard, et al, 2000: 69); in fact, Mrs. Dorking seemed so troubled by this aspect of herself that she felt she had to thank the interviewer for tolerating it. This would suggest that Platonic notions of beauty and youth play an important part in the regulation and exclusion of older people, as well as those with a disability (Marks, 1999).

Acceptance of the way that society values the supposed characteristics of youthfulness (such as beauty) over and above those associated with 'old age' (such as passivity) was also a feature of data generated by Mrs. Clark, one of the case study participants. Here, she explained why she did not go out as often as she would like:

'I think we go on enough outings don't we according to our age we do. They take all the young ones; they don't take us old stagers (Mrs. Clarke, age 80, Lulworth Court).

By defining herself in terms of her age Mrs. Clark managed to explain away her lack of contact with the outside world. Moreover, she used her age more than once during the interview as a reason for not being able to do some of the things that she once did:

'No I can't sing at my age....if you are getting old like me you can't (get to church)...you can't always be on top of the world when you are getting old can you

(Mrs. Clark, age 80, Lulworth Court).

It seemed to me that Mrs. Clark had internalised dominant discourses about 'old people' being passive and powerless to such a degree that even she used it to damage any potential she had for doing and being things differently.

The same could also be said of Mrs. Kitchener, a participant from the second sample group, who accepted - albeit begrudgingly - the powerless position she found herself in during the sale of her house:

(My house) has recently been sold but I don't know much about it really. My nephew is doing that. Sometimes I would like to know more, but I think they think I am an old goner you know. That is it. They do come, and I ask them to tell me but...

*How do you mean when say you feel that you are an old goner?*

You see if I wasn't so old they'd - you know I should be doing more myself. But now it is sort of left to my nephew or anyone. Well he is the boss of it. But yes... he does it very well, but sometimes I like to know things and I don't.

(Mrs. Kitchener, age 84, Purbeck Lodge).

Although Mrs. Kitchener did not doubt the competency of a younger male relative to handle her affairs, she clearly felt that as she was seen as 'old' she was being kept in the dark about a matter that was important to her and which she wanted to know more about. The interplay between social divisions based on age and micro processes of oppression was also evident when Mrs. Kitchener spoke of the careless way that personal items were laundered and thus returned to her in an inferior state. When asked whether or not she complained to anyone about it Mrs. Kitchener replied:

I have said something but they don't take much notice of you. They just think oh well it's that old girl, she is complaining again, you know (Mrs. Kitchener, age 84, Purbeck Lodge).

In both instances, Mrs. Kitchener accounted for the invisible position she found herself in by referring to her age (and gender) rather than other possible characteristics such as where she lived.

Even with a small research population, participants from both the first and second sample groups all had very different economic, educational and domestic backgrounds and personal resources from which to draw upon to rationalise any sense of exclusion or loss of identity that they might of felt, it was invariably the social category of 'old' which was mobilised to explain why they could no longer expect to have or achieve the things that they wanted to do or be. Take for instance the way that Mrs. Dunn, one of the oldest participants from the first sample group, justified having to do a lot of her living in one relatively small space:

'I heat this room up, so it makes it nice, so that now that I am old I don't mind it too much in the one room...This is quite enough for me isn't it...I think it is at my age I don't want anything more. I don't want a bigger place or more rooms, not really. I have my meals here you see my mid-day meal

(Mrs. Dunn, 93, Encombe House).

Like people with a disability, older people are 'taught to know their place on the social ladder' (Kitchen, 1998: 346) and that, in this instance at least, that place was a room some 12 square metres in size. Moreover, as Mrs. Dunn goes on to say: A person cannot expect much out of life when they are old.

Yes, so really I am all right here. Yes, I can't grumble. And I am in my old age now, so like I say I can't grumble

(Mrs. Dunn, age 93, Encombe House).

Why shouldn't Mrs. Dunn, or indeed any older person who lives in a care home, grumble? Might it be, as Mrs. Dunn implies, to do with being 'old'? According to Freire (1970, quoted in Kitchen, 1998: 346) rather than complain, those who are oppressed 'fatalistically accept their exploitation', and so rather than being a generational characteristic, as is often argued (Nystrom and Segesten, 1994), not complaining might actually be a sign of repression. A view that might explain why a sense of hopelessness and weariness underpinned many of the narratives produced about 'being old'. Mrs. Peters, a participant from the first sample group, was asked about her health, for example, to which she replied: 'I am very tired, I am 85, and I get terribly tired, I just can't be bothered' The inertia that Mrs. Peters expressed after stating her age suggested that she was tired of being 'old' as well as (or maybe even rather than) physically exhausted. Expressions of general fatigue were also expressed by Mrs. Clarke: I don't know it's age I expect. I am getting old you know. I am just as tired when I get up as when I go to bed. That is the truth'. Shotter (1997, 126) points at, that feeling tired is not simply a physical state, but also a psychosocial response to the particular circumstances that a person finds themselves in: 'tiredness is having to live a life not of one's own, a desire to have a voice and be listened to seriously, as of right'.

The physical and psychological impact of the ageing process is a causative factor in depression amongst older people (Baldwin, et al., 2002). While this study did not set out to investigate either the prevalence or experience of this condition, another clear theme in the data was loss and loneliness. Data from all four case study participants revealed some degree of sadness or loss in that person's life: Mr. Smith spoke frequently of how much he missed his wife; Mrs. Green said how her son and husband had died that year; Mr. Brown's stepdaughter described how upset her stepfather would sometimes get:

I say I know what you are doing and I agreed that if he wanted to phone me which he does occasionally when he gets a bit upset, he has tearful days, then he will phone to me and talk to me for a minute or two and then he is gone. And he will say I am sorry I bothered

(Mr. Brown's stepdaughter).



The need for emotional support was greatest whenever Mr. Brown was feeling low. Unfortunately for Mrs. Clarke, whose only living relatives – her daughter and grandson – lived in America, it was more difficult to find such support. As she said:

I feel it dreadful sometimes, because everybody has gone. Moany old life with nobody to come isn't it. Friends die off because they are getting old, but you can't help that can you. Relations you should see don't come

(Mrs. Clarke, age 80 years, Durlston Court).

Mrs. Clarke seemed particularly saddened by the lack of contact that she had with family and friends. As did this woman:

'I feel low all the time...because I don't see any of them, my son keeps a pub the other side of town and of course he is very busy. He and my grandsons come down on Sunday afternoons. They only stay for about 5 minutes; they come in and bring in any shopping I want done, which isn't much, give it to me say hello and goodbye. Any my daughter can't come over very often, so I feel alone all the time

(Mrs. Kent, age 94 years, Purbeck Lodge).

Loneliness is one outcome of growing old, which affects some individuals' ability to feel a part of everyday life. Finally, the interpretation of this data about health status is that people clearly have very different experiences of mental and physical ill health, underlying these 'different embodied experiences' however, often lies a common sense of pain and social isolation (Parr & Butler, 1999: 2).

## **8.6 Summary**

This chapter has discussed how ill health impacts on peoples' capacity to take part in everyday life. It explores an influential factor in exclusion which many social studies of dementia and disability avoid, namely, impairment. Rather than ignoring experiences of impairment, the charting of 'the myriad of ways in which people with mental disorders are disabled' (Mulvany, 2000: 600) has highlighted a range of physiological causes of exclusion including difficulties with remembering, speaking and mobility.

The chapter also explored the emotional impact of dementia on participants. This highlighted the possibility of 'emotional oppression' as others did not always seem to appreciate the effect that cognitive decline had on people (Marks, 2001). This led to a discussion about the impact of physical impairment, which showed how isolating poor vision could be for certain participants. Finally, the chapter considered biological processes related to ageing and its impact on peoples' capacity to participate in everyday life. The main feature of this discussion was how rudimentary some causes of exclusion are – for example, not moving for fear of falling.

## CHAPTER TEN

### Personal strategies of resistance

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#### 10.1 Introduction

Questions have been implicitly raised in the four preceding chapters as to how an older person with dementia deals with adverse economic conditions, organisational influences, poor mental and physical health and the ageing process. This chapter addresses this issue and explores the strategies that individual participants with dementia used to counter exclusion processes. Five different strategies of resistance are explained and presented in this chapter. These are (i) distancing oneself from others (ii) aligning oneself with others (iii) recounting past pleasures and routines (iv) deploying individual resources, and (v) thinking rebellious thoughts. Identification of these strategies was achieved by drawing on the growing body of work that recognises that older people (with dementia) seek to find ways of managing the self and this condition (Reed and Roskell-Payton, 1996; Lyman, 1998; Gillies, 1997; 2000; Clare, 2002; Woods, 2001). It is argued in this chapter that by exploring individual strategies for resistance one can begin to understand what it might feel like to be, or not to be treated as a citizen (Shotter, 1993).

#### 10.2 Distancing one self from others

The process of distancing one self from other people and places was characterised in the data by activities of either a spatial or sociopsychological nature. Activities of a spatial nature involved a participant with dementia making sure that there was a physical distance between themselves and other people or places. The manager of one of the Carstairs Trust homes provided an example of this strategy when he described an incident involving a case study participant. Note in particular, the undertone of disbelief about *her* actions, rather than those of the bed and breakfast proprietor:

She actually went to the bed and breakfast the other day to see if they would put her up, because the gentleman here who was being quite disruptive let's say and this affected Mrs. Clarke to the point where she went off down the road, and the bed and breakfast place phoned us and said 'do you have a Mrs. Clarke that lives with you because she is trying to book herself in here?' So her reaction to sort of disruption was to go out and get away from it

(Manager of Lulworth Court, talking about Mrs. Clarke).

Mrs. Clarke was said by the manager to want distance between herself and the home and certain people within it. In telling the story of Mrs. Clarke's attempt to achieve this, the manager revealed how he saw Mrs. Clarke's behavior as an understandable reaction to her immediate environment but was not surprised that she should 'be returned'. Although Mrs. Clarke did not refer to this particularly incident during her interview, she did speak of not going out as often as she would like; at one point she suggested it was because she had been instructed not to. She said, 'I mustn't go out on my own, I have been told I mustn't'. At another point she said it was because she herself felt unsafe, she remarked, 'I don't like going out on my own any more I don't feel too sure. So it is best not to do it isn't it'. Therefore, the act of leaving the care home *might* be interpreted as a way for her to reaffirm her identity as a woman who was able to make her own mind up about what was best for her and to take responsibility for her own accommodation needs, rather than relying on the services provided by others. So, rather than simply being a reaction to the behaviour of a certain other resident, her action could be interpreted as communicating a much wider message:

Local acts of resistance are not always an expression against specific, local processes of domination, but may be reactions against wider, national oppressive policies (Kitchen, 1998: 352/3).

An older person with dementia has little if any choice about where to live if they are deemed in need of long term and intensive help and support, Mrs. Clarke seemed to demonstrate one way of communicating that.

In Chapter 2 it was explained how the medicalisation of dementia has meant the behaviour of people affected is often seen as symptomatic of the illness rather than as a valid form of communication (Goldsmith, 1998). In the context of this study, the process of physically distancing one self might be construed as a means of convincing oneself and others of one's individuality (Cohen and Taylor, 1992). Mrs. Green had been the manager and proprietor of a local bookstore; hence, she was a woman with a strong bourgeoisie identity. Indeed, she recollected at one point during what was quite a fragmented interview the full extent of her managerial responsibilities. She said, 'I must have had about five people working for me'. Within the boundaries of the care home, the semi-public spaces of the corridors may have seemed to her like the shop space she once owned and took sole charge of. Here the manager of the care home in which she lived described how sometimes she could be seen physically distancing herself from others within the confines of that space:

We have certainly seen her push people out of the way when she is walking down the corridor. May be a resident that has upset her in the past over something. She will just give them a push

(Manager of Durlston Court, talking about Mrs. Green).

By forcibly creating a physical distance between herself and other residents, Mrs. Green communicated not only her ability to control semi-public spaces but also her identity as an assertive woman. In contrast to the amount of physical distance that Mrs. Clarke appeared to want, Mrs. Green seemed to prefer to preserve her identity within the confines of the home:

The front door is open, but I have never found her out there saying she is actually going. She wanders out into the garden. She doesn't go to the boundaries saying I have got to get out of here. So there must be something that says to her that – I mean if she really wanted to go she would get to the boundary or try and force the gate or something

(Manager of Durlston Court, talking about Mrs. Green).

Shurmer-Smith and Hannan (1994: 41) would probably suggest that the reason why this particular woman did not leave voluntarily, or ask to leave was because she knew that she could not go home and so had learnt to shift her horizons to her living space in order to survive.

Living in a care home has been described as a type of 'exclusion through segregation or differentiated inclusion' (Ravaud and Stiker, 2001: 504). This is because a care home, which while physically part of a community, exists to separate and house certain 'types' of people – in the context of this study, older people (with dementia) – away from others who live in that community. The complex and contradictory role that a care home has to play in an older person's life may explain why some other participants seemed to distance themselves conceptually (rather than physically) from other people in the home. For example, Mrs. Dryden, having spent much of her married life living in India with her husband who was a Gherka, was a woman with a particularly strong national identity. The process of distancing herself (and her husband) from other people in the home might therefore be seen, as a way for her to maintain that cultural identity. She said, 'English people keep themselves to themselves, we haven't tried very hard to get to know people'. She and her husband wanted to keep themselves to themselves because they believed that is what English people do. The confluence of individual and collective identities that Jenkins (1996) discusses has resonance here. He contends that our individual sense of who we are and the identities that we feel we share with others are in fact indistinguishable from each other. This helps us to understand the complexities of the situation that Mr. and

Mrs. Dryden found themselves in: only by having people to keep a distance from could they keep their sense of identity.

Because the foundations of our identity are considered inextricably entwined with the relationships that we have with other people (Twine, 1994) it might be reasonable to assume that any exclusion from people is necessarily harmful. Indeed, this may be what the care workers of Encombe House thought, as they brought people with dementia into the lounge on a daily basis. In another example of a participant distancing herself from others, the importance of being able to interact with the 'right' type of person is made clear. Mrs. Dunn, who lived at Encombe House, was asked how she got on with other people in the home. She replied, 'we get on all right, but you wouldn't call me a – you know – a big mixer. I don't mix a lot'. In much the same way as participants in the study by Reed, Roskell and Payton (1996: 556) sought to manage themselves according to social conventions; some people in this study were also inclined not to get too close to other people. As a single woman for over thirty years, perhaps Mrs. Dunn preferred her own company to anybody else's in the home, as she said. As she said, she was 'happy and satisfied' with the care home because there was not, in her opinion, 'too many neighbours, you know chatting and hanging round'. Being aloof, particularly with people who she saw as having nothing purposeful to do, was an attitude that ensured distance between herself and others. A similar interpretation might be made of Mrs. Windsor's reply when she was asked if she sat at the same place with the same people for her meals. She replied, 'oh no. I am the only one who has got a picture of my grandmother'. I think she thought the question was about the sameness of people rather than the same people; hence, she mentioned the one object she could think of which singled out and symbolised her unique identity as 'Mrs. Windsor'. Sabat and Harre (1992) who have initiated the debate in dementia studies about the nature of identity would probably see the language used by these women as evidence of the true inner self remaining intact. Similarly, the notion of personhood has resonance here, as these participants were clearly aware of their 'self' as a

unique human being (Kitwood and Bredin, 1992). As a strategy for social inclusion, then, distancing one self from others is an effective one, as it keeps intact ones sense of who we are and how we wish to be seen by others.

Given the nature of 'identity work' that people involved in this study seemed to be engaged in, the idea of the 'self contained' individual on which the notion of personhood depends, might be questioned (Hockey, Billington and Strawbridge). As Nolan (2002: 203) suggests seeing people with dementia as totally unique individuals does not really 'capture the independencies and reciprocities' that human relationships are made of. The discursive strategies of two participants during the interview process, demonstrated the way in which not only are identities inextricably entwined with other people but also how the process of distancing our selves from others is part of human nature. Take for example the following conversation that arose due to Mrs. Green having to fix her hair after a hair slide fell out:

*Your hair looks very pretty.*

I am not sure you mean that, I don't know.

*Do you have it cut here?*

I do sometimes or I have done in the past, but that is purely because the lady who does it has this - done her apprenticeship here. Sorry I don't think you ought to have come

(Mrs. Green, age 77 years, Durlston Court).

It could be that as Mrs. Green did not wish to appear to the interviewer as a woman disheveled, she wanted distance between her and the interviewer to avoid the co-creation of that identity. Like participants of another qualitative study of social exclusion, this woman devised tactics to preserve herself as a 'decent respectable' person (Reay and Lucey, 2000). To see and treat Mrs. Green as a totally unique individual is arguably



oppressive as it would involve separating her from ‘the great body of humanity’ to which she sees herself as being a part (Ryles, 1999: 605).

The other participant who I think tried to distance herself from the interviewer in resistance to the identity she feared was being co-constructed, was Mrs. Clarke. Before exploring the nature of Mrs. Clarke’s discursive strategy it is important to elaborate on the context of her interview. First, Mrs. Clarke was interviewed in the presence of not only a care worker, but also the senior investigator on the project. She was therefore being asked questions in a room with three other people, two of whom she would not have known very well. Second, throughout the duration of the interview a man was outside cleaning the windows of the home; his presence was to prove vital in the resistive strategy that Mrs. Clarke deployed. During the interview Mrs. Clarke was invited on two separate occasions by the interviewer to voice her opinion about the home, both times she immediately referred to the activities of the man outside. The exchange was thus:

*What if you changed your mind (about your menu choice) would you ask?*

Well I shouldn't bother no. I wouldn't bother to cause trouble, I don't believe in that. That man is getting to everybody's window up there. He has gone in all the windows that man. He is down on the floor now, He is pointing at us, he is coming here now....

*If you knew someone who was coming to live here what would you tell them about it?*

About this place. oh I don't know I'm not going to say nothing about it. It is all right isn't it dear? It is quite all right. I am not going to run it down. That man has got ever such a long ladder. He is going to put it right up to the top of the roofs. He can't climb all that way up can he?

(Mrs. Clarke, age 80 years, Lulworth Court).

It might be suggested that by referring to the man outside Mrs. Clarke dissociated herself from not only a potentially contentious topic but also from being seen as a whistle-blower,

thereby keeping intact her identity as a woman who was ‘good fun’ and ‘good company’

<sup>36</sup>. The subtle and productive strategies that individuals engage in to counter and maintain identities are not generally seen as such by others (Orona, 1997).

### **10.3 Aligning one self with others**

It is suggested that people with dementia use the same strategies to deal with the situations they face as they have used throughout their life (James and Sabin, 2002). As with its sister process of distancing, the process of aligning self with others often entailed extensive social activity on the part of the older person with dementia. This activity was characterised in this study by participants describing the ways in which they made sense of their environment. For example, when I asked Mr. Brown how he spent his time in the home he described his activities as being rich with meaning and purpose. He replied, ‘working with the boys’; ‘Work with the boys do you’ I restated. Yes, best we can’. I then asked him what sort of work he did: ‘Just labouring work’ who else do you that with, I asked: ‘Three of us together going all round’. Mr. Brown was busy, and so he felt were the other men that he knew in the home. According to Billington, Hockey and Strawbridge (1998: 40) we are ‘at one with ourselves when we have a role to play, when our sense of identity is confirmed in our relationships with others, and we have a recognised place in society’. This certainly seems to be the case for Mr. Brown. Unfortunately, because the behavior of someone with dementia is often pathologised and seen as symptomatic of their condition rather than, as a strategy for identity maintenance (Sabat and Harre, 1992) the ‘identity work’ that Mr. Brown engaged was not perceived by his key worker as such. From her perspective Mr. Brown’s behaviour was incessant and meaningless, she said, ‘he wanders about. He doesn’t sit still really. He is up and down wandering about’.

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<sup>36</sup> This was how she was described by the care worker in the separate interview that was conducted with her as part of the case study.

The influence of care workers perceptions on the identity of people with dementia is noted in the literature (Kitwood, 1993; Harding and Palfrey, 1997). However, in the context of this study, that influence did not preclude Mr. Brown from either seeing himself as working man or from aligning himself with the workforce. Elsewhere in the interview Mr. Brown revealed how he knew his place in the social world was no longer the workplace but nevertheless felt there was no other place suitable for him:

‘I am supposed to have retired a long time ago, but I keep going back to work, I can’t leave it somehow. I should leave it. But I get up in the morning and go to work...I get up lots of times when I have no need to. It is funny why I can’t get into staying at home...I am on the sick list now as a matter of fact

(Mr. Brown, age 84 years East Wing)

It would seem that the identity of men is grounded in the world of work (Hutter and Williams, 1981). Consequently, someone like Mr. Brown – who had spent all his adult life working in the same car factory - was extremely reluctant to relinquish it as a basis on which to construct his identity. Even the patient identity he assumed was part of that working role. This observation is similar to that made by Braudy Harris and Durkin (2002: 172) who suggest that because of dementia people affected replace old social roles with ‘new roles or adapted previous roles’. Mrs. Green’s sense of identity also seemed to be maintained through this process. While she would physically distance herself from other people living in the home, the manager revealed how she was not like this with the people who worked at Durlston Court:

I found that she is with me a lot of the day.

*What do you mean by that?*

Following me around, helping me, being part of whatever I am doing. Standing when I am on the phone, being with me. She likes to help with the tea trolleys and

help give the biscuits out. And she likes to come in the kitchen and likes to help us wash up

(Manager of Durlston Court, talking about Mrs. Green)

Mrs. Green was reported to occupy spaces within the home that clearly aligned her with staff rather than other residents. It is reasonable to suppose that her former role as a bookstore manager explained why she accessed and controlled certain spaces within the home in the way that she is reported to have done. It is not only the identity of men which is grounded in the world of work.

The process of aligning one self with other people and places also entailed making a contribution to care home life. This may have been in the form of a domestic contribution, as was seemingly the case for Mrs. Green, and also for Mrs. Dunn who said, 'I tidy up here you see and I do a bit here most days'. This particular strategy has with resonance with other research, which suggests that a woman's preference for a clean and tidy house is to help them think they are functioning well (Clarke, Dyer and Horwood, 1998). For others it was about getting involved with things going on in the home. Mrs. Clarke, for example said, 'well if there is something scheduled to do I will do it' while Mrs. Windsor welcomed the opportunity to partake in a lifelong pleasure. She said, 'I like going out in the garden and pottering about'. These insights into how people perceive of their contribution to daily life are easily overlooked when meanings of inclusion are seen as being about engagement with macro systems and structures (such as employment and politics).

The notion of 'intimate citizenship' is a useful one to introduce at this point, as it extends the 'principles of citizenship to interpersonal relationships' (Faulks, 2000: 124). A recurrent theme underpinning the interviews with Mr. Smith was his desire to make friends with people in the home; here he described how important he felt it was to be able to do this:

I make friends quite easy, you know, and I think a lot of it, if you talk to them about anything really you get on all right. That is what I think anyway.

*That it is important to talk with people?*

That is right. I don't like someone - I mean there is one man that comes and sits - he is quite friendly but he doesn't say anything, you know, he hasn't got the art of conversation but he is a very nice, well-mannered man, you know. But I like talking you know.... I talk to everybody; well everybody talks to me then like you know. When they just come here you start talking you know and get on with life

(Mr. Smith, age 77, Encombe House).

As with participants in a study by Reid, Ryan and Enderby (2001), not only did Mr. Smith seem to perceive a higher level of disability in others than he did in himself, but social interaction also was an important source of satisfaction to him. A possible reason why Mr. Smith expressed this strategy for inclusion over any other was because he had always seen himself as a sociable man. At least that was the sort of person he wished me to see him as. Goffman (1959) argued that the way we present ourselves, particularly in an interview situation, reveals the way in which we want others to see us as social actors in the social world. For Mr. Brown the interview provided him with an opportunity for realignment from a 'resident with Alzheimer's' to being an ordinary man. This was because at the end of the interview I asked if it would be okay for me to come and talk to him again; he said, 'I could stay and talk to you all-day and go to the pub and have a pint and you have a ... whatever, what do you drink?' By aligning himself with me on the basis of a common British pastime Mr. Brown became a man who wished for the same 'episodic excitement and release from constraint' as most other people in mainstream society (Cohen and Taylor, 1992: 131).

#### 10.4 Recounting past pleasures and routines

The therapeutic value of reminiscing for older people is well recognised; although as Bornat (1997) points out, people with dementia are often excluded from such opportunities. In the interviews conducted for this study, I believe the recounting of past pleasures and routines provided participants with an opportunity to 'to seize authority' with respect to the topic of concern (Och and Capps, 2002: 127), which in turn, it is argued, allowed individuals to exercise intimate acts of citizenship.

Of the ten participants who made up sample group one, six spoke of hobbies they once enjoyed doing. As well as embroidery and sewing, gardening was a popular pastime amongst participants. Mrs. Darling said how she 'used to do a lot of gardening' and Mr. Brown agreed and described how it used to help him unwind after work:

Oh I always used to like gardening. I used to come home at 6 have a bit of bread and cheese and go out to the garden.. I used to love it.

*Do you miss gardening?*

Yes, you do I think. I think that is one thing I do miss

*What did you grow?*

Everything, you know carrots, spuds, everything that went for a meal

(Mr. Brown, age 84 years, East Wing).

Reminiscing about the daily routine he had outside of work allowed Mr. Brown to express how much pleasure he gained (and missed) from being a gardener. It also provided him with a valuable topic of conversation with which to fuel the interview. Finding that participants were keen to talk about memories from the past is consistent with previous

work in this field suggesting that it is a constitutive strategy to resisting the stigma associated with dementia (Barnett, 2000).

Having a hobby is said to provide people with an important resource from which to escape the drudgeries of everyday life (Cohen and Taylor, 1992). Mrs. Green felt she had been uninteresting during the interview because she had no pastimes to speak of. She said, 'I am not very interesting I am sorry, one of my hobbies is sort of hiking in the country', seemingly aware of the added dimension that this can bring to a conversation. Having something to talk about was also important for Mr. Smith, as he too spoke extensively about a life long passion that he had for music and dance:

I love dancing anyway. I love dancing to music. If I go somewhere and there is music and dancing, I just can't sit down. I honestly can't. I am up and my feet are going like this all the time. And it is funny I should say this now. I remember years ago and I had never danced...

*(the participant goes on to tell a story about how an older woman taught him to dance when he was only nineteen years old).*

(Mr. Smith, age 77, Encombe House).

Mr. Smith's story about how his life had been defined by music and dance allowed him to assert his masculinity. Moreover, it provided him with a chance to clear out a 'small subjective spaces uncontaminated by institutional reality' (Cohen and Taylor, 1992: 41). Dancing with a woman was something that Mr. Smith still very much enjoyed doing and from what his care worker said, not only did he still have the opportunity to do it, but his visual impairment had enhanced the intimacy of it:

He says 'you are my eyes' he says. Because we talk about Christmas he likes dancing. And I say 'okay I will be your eyes while we are having a dance'. And he says 'oh good'. He likes dancing. Things like that he misses being able to do

(Care worker, talking about Mr. Smith).

The closeness of their bodies in dance meant that his visual impairment was no longer an issue. In this sense, Mr. Smith seems to have ‘the self is reconstituted’ – that is, it is incorporated into new narratives about himself (Lyman, 1998).

Another strategic function of talking about past pleasures and routines was to assert the type of person that they still are or believe themselves to be. Continuity of the self by this means is another easily overlooked aspect of social inclusion. The process of reflecting on the type of person they once were was an important means for a person to stay connected with their pre-dementia identity. For example, the interviewer passed a comment about having seen Mrs. Windsor gardening when she last visited the home. She said ‘I have always done it’. Similarly, as Mrs. Windsor spoke about the many photographs she had in her room of her children and grandchildren, and how much she enjoyed having them come and visit, she said, ‘I have always had them around’ and ‘I like to be happy with people, I always have done’. By describing the activities that she did now in terms of the things that she always done this woman stayed connected or aligned with her own sense of self.

Participants were keen to describe the things that they did at the time of the interview in terms of a continuum of their self-narrative. Another participant rationalised her wanting to go out in terms of something that she had always done:

I do like to get out. I don't want to be stuck in here all day. I have never been used to it. I used to go regularly (to the church) in the older days, always have been, all my life really

(Mrs. Clarke, age 80 years, Lulworth Court).

By talking about the things that she used to do it seemed to me that Mrs. Clarke was able to reclaim her religious identity, and more critically, rid herself of the identity of a woman



pinned to her locality. A similar strategy was evident in a narrative, albeit fragmented and brief, of Mrs. Darling. The smell and sound of coffee being served to other residents during the course of the interview prompted the interviewer to ask Mrs. Darling about her liking for a mid-morning drink. As a retired art teacher the same smell and sound seemed to reminded Mrs. Clarke of one of the pleasures of her working day. She said, 'there was always a pot of coffee in the morning at school'. Unlike the routine of the care home, the morning ritual of the school staff room was something Mrs. Darling could speak confidently about. The comment allowed her to relive fleetingly the school culture and her part within it. The fluidity of identity is discussed widely in the sociological literature - the basis on which a person identity is constituted is never any one way of being. This short excerpts, reveal how the 'disabled identity' in particularly is 'multifaceted and fluid concept, rather than a fixed concept' (Reeve, 2002: 504).

### **10.5 Deploying individual resources**

The ability of people in the very early stages of dementia to cope with confusion and memory loss are well documented (Keady and Nolan, 1995; Keady, 1998). This body of literature outlines a model of mechanisms which people affected use to deal with cognitive change and decline (Keady, 1996). *The types of resources identified in the model include*, 'covering up' and 'surviving/maximizing' both of which are said to help people adapt to and accept dementia (Woods, 2001). In the context of this study, the basic principle underlying this work, namely, that people with dementia are like anybody else deploying different resources to deal with everyday life, proved extremely useful when analysing for personal strategies of inclusion.

Social theories of power remind us whenever people interact they bring resources to that interaction (Charon, 1995). People with dementia in this study were no different. A recurrent theme in the narratives of Mr. Smith was how resourceful he was in dealing with loss and change. As well as being diagnosed with a vascular-type dementia, Mr. Smith was

visually impaired; he had been widowed for almost two years and gave up his house to move into Encombe House when his sons told him they thought he was not safe living on his own. This man had therefore experienced multiple losses – his memory, his wife, his sight, his home and his status as a father. The way in which Mr. Smith dealt with the major changes in his life was by seeking to stay connected with not only other people but also his own sense of identity. He said at one point: ‘when you come here you start talking you know and get on with life’; and at another, ‘I will talk and have a laugh, talk about anything really. Oh yes, too true. Life is too short my love’; and at another, ‘I will talk to anybody, good God yes. A few of (the other residents) are a good laugh. It is no good moping is it. Life is too short’. Clearly talking about his ability and keenness to get on with other people in the home had become so habitual for Mr Smith (at least in the context of the interviews conducted for this study) that it provided an effective way for him to structure his experiences and philosophy on life (Bruner, 1987). Charmaz (1994) discusses the capacity of men who are chronically ill to preserve their sense of self by maintaining ways of being in the world. With Mr. Smith it is possible to see how he maintained coherence through loss and change by being ‘Mr. Smith’ – sociable, friendly and upbeat.

Behaviours that reflect a person’s individuality such as friendliness and humour are considered a key indicator of well-being (Hasselkus, 1998). The interpretation of data produced by this study was that such behaviours were not only a sign of a person’s psychological state but also indicative of how a person sought to deal with exclusive processes. A recurrent theme in case study material pertaining to Mr. Brown was how resourceful he was in dealing with lack of control. In one of the interviews with Mr. Brown he revealed how he thought it was sensible to make light of the ‘bodywork’ that being cared for entailed (Twigg, 2000); here he recalled what it was first like when the care workers invited him to take a bath:

They will bath you. When that first started it started a lot of chatter I can tell you. It seems to work quite well. The boys come down here and say ‘oi your turn’

(Mr. Brown, age 84 years, East Wing).

Mr. Brown engaged in a certain amount of banter with the other men in the care home whenever it was 'his turn' to be bathed. Mr. Brown's tendency to make light of being bathed by young women was also remarked upon by his care worker. She said, 'he will come out and say she tipped water all over me if he has been in the shower. And make a joke of it'. Mr. Brown described the experience of being bathed in a similarly comic tone: 'the girls bathed us we had some fun and games then I can tell you'. The use of humour by Mr. Brown when his naked body would have been exposed to young women might be interpreted as a means for him to deal with the embarrassment of that situation (Billig, 2001). Alternatively it might also be seen as a valuable opportunity for him to maintain and demonstrate the special identity he had in the home of being a joker (Cohen and Taylor, 1992).

The personal resources that people with dementia use to deal with everyday dilemmas and discomforts are usually ones that an individual has always used for solving problems (James and Sabin, 2002). For Mr. Brown it was to maintain the social personae that he created for himself within the home, which was to not be serious or downbeat. His key worker said, 'he is very funny with the other residents and will have a laugh with them... He is funny'. The process of adapting to impairment to was part of the process of presenting oneself (Goffman, 1958). From the way the care worker described Mr. Brown it would certainly seem that humour was a core characteristic of his identity. She said, 'I think anybody that you speak to would say you can have a laugh with him. He is funny'. She also described how he routinely used humour in his interactions with other people in the home:

He is very funny with the other residents and will have a laugh with them. We have got one lady who likes him to help her put her feet up on the stool and he will sit there and he won't do it until she asks him. And he will laugh and she says 'it is not

funny'. He says well you have to ask me if you want me to do that, I don't know. He is quite witty. That is basically all he does really

(care worker, talking about Mr. Brown, East Wing).

In the same as Mr. Brown probably used humour throughout his working life on the factor floor of a car plant to alleviate boredom, in the nursing home he continued to use it to make everyday life bearable. The ability to produce a laugh was clearly the characteristic which defined Mr. Brown's membership to the resident group (Collinson, 1988: 164) - it 'summed him up'. This interpretation of how Mr. Brown used humour to maintain a sense of identity and control draws upon the sociology of work literature, specifically the link that it makes between humour and resistance. The function of humour in the workplace is described by Collinson (1988: 165) as a 'form of resistance both to the tightly controlled repetitious work tasks and to the social organisation of production in the home'. In the context of this study, it is argued that is not so much the 'shop floor controls' that were being resisted but certain care practices within the care home.

As well as the two male case study participants, Mrs. Clarke also used humour as a way of reversing exclusionary processes. Mrs. Clarke was interviewed in the presence of her key worker and so this transcript revealed the type of 'interactive data' that one normally gains from focus groups (Wilkinson, 1998). One particular exchange between Mrs. Clarke and the key worker, over the issue of bathing, shows how humour is used to mediate a challenge to the way care practices are organised within the home:

And do you tell people when you want to have your bath or shower? No they tell us when we have got to go don't they dear. Care worker: well they ask. They ask if they can, if you don't have it, they will throw you in it. That's a laughable joke. I am sorry about that you shouldn't have put that

(Mrs. Clarke, age 80 years, Lulworth Court).

It would seem that the pleasure derived from seeing the ‘powerful discomfited’ (Billig, 2001: 43) was worth exaggerating the tale about how staff organised this aspect of her personal care. The use of humour as a means of resistance demands an awareness on the part of the joke teller about the oppressive nature of the situation they are in. This also seemed to be true of Mr. Brown as the one other time he used humour during the course of our interview was to highlight how little he felt the staff thought of him. The following exchange occurred someone knocked on Mr. Brown’s bedroom door and I wondered aloud if it might be someone looking for him. He said, ‘they would soon find you, but they wouldn’t worry about me. *Don’t you think they would?* No, I like to pull their legs about it seems the smart thing to do’. Mr. Brown humoured care staff about their seeming lack of interest in his whereabouts because he felt that they did not really care about him.

#### **10.6 Thinking rebellious thoughts**

Another strategy that some participants used for dealing with the aspects of care home life, which they found exclusionary or at odds with the sort of person they were or wanted to be, was sited inside a person’s head. Scott (1999) advances the idea that we all have within us a rebel that silently challenges the social order in which we find ourselves. Although this author’s thesis is based on the situation of peasants, the actual idea of a ‘rebel inside the head’ is a useful one for exploring the hidden modes of resistance deployed by older people (Wilson, 2002). Equally, the idea was drawn upon to illuminate our understanding of how an older person with dementia might be seen as dealing with the situation they found themselves.

Given how dementia impacts on the brain, for some affected, the ‘rebel inside the head’ was most evident in relation to things happening at that time rather than things that had happened in the past. Mrs. Green, for example, who seemed unclear at certain points during the interview of its purpose, revealed how defiantly she was thinking about the whole process. She remarked, ‘you can’t help wondering in a case like this - one can’t help

wondering what you are trying to get out'. By expressing her doubts about the interview process, as and when she had them, Mrs. Green asserted herself as a woman who knew her own mind and who was prepared to articulate what went on inside it. The capacity of people with dementia to rebel against the disabling influences that they face was evidenced by the production of this type of narrative. Given how the last thing that Mrs. Green said to the interviewer – or to be more accurate the last thing she said to the interviewer that was recorded - was, 'I think we better close down' one might suppose that such a strategy was effective.<sup>37</sup>

The argument made in this section is that the way some participants said they thought about things revealed an otherwise hidden site of resistance. It is evident from talking with other residents in the homes how widespread this strategy is. For example, one participant vocalized the rebel inside her head, as she described the frustration she felt having to rely on others for help and assistance:

Well, at first I was in a wheelchair here, and there were a lot of other people in a wheelchair you see, so when you go down to meals I was dying to get back, but of course you've got to wait, and um, well I didn't mind it at the time, but I used to think, 'oh isn't this a nuisance', you know

(Mrs. Wells, age 97, Lulworth Court).

The frustration that Mrs. Wells seemed to feel about not being able to get back to her bedroom, as and when she wanted to, was played out in her head. The actual way in which thinking rebelliously worked as a strategy to evoke a sense of identity, was also evidenced when Mrs. Wright of Lulworth Court revealed what she thought in response to visitors' comments about the loveliness of her flat. She said: 'everyone that comes says you have got the flat lovely. I thought yes. It might be lovely to them but I am always thinking about my home'. She kept on thinking about her home as a mark of defiance to others who

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<sup>37</sup> The role of non-disabled researchers in disabled peoples' experiences of oppression (Stone and Priestly, 1996) is explored in more detail in section 10.3.

believed that where she was, was a nice place to be, and so as ‘to escape’ from the institutionalised reality that she was in (Cohen and Taylor, 1992). Unbeknown to others, a person with dementia might also be thinking defiantly in relation to the situation that they found themselves in. While there was little evidence of that happening from the qualitative data collected for this study some passing comments, which were made, suggested this line of enquiry might be worth pursuing. For example, Mr. Brown seemed aware of the potential he had for creating ‘problems’ for care staff when he vocalized the type of thinking that went on in his head. He said, ‘you could be awkward if you wanted to be’.

### **10-.7            Summary**

This chapter has discussed a relatively unexplored aspect of social exclusion, namely, the subtle and various ways in which individuals work to counter it. The chapter has focused on the particular strategies deployed by a small group of older people with dementia living in care homes. This in turn highlighted the hitherto unknown extent to which older people affected by cognitive impairment have the capacity to actively create opportunities for ‘identity work’.

*In the context of this study, some of the strategies that people engaged in (such as talking and remembering) might be easily overlooked or undermined as a route to inclusion. Similarly, certain behaviors can be medicalised and or misinterpreted and thus not seen as a valid means of communicating ones sense of identity or oppression, as was argued to be the case with Mrs. Clarke. An important aspect of this interpretation is that the process of inclusion is an individualised one: no two people are likely to seek to reverse exclusionary processes in exactly the same way. However, from data analysed in this study, the desired outcome would seem to be the same for this small group of people – that is, to demonstrate that ‘dementia’ is just one of many other identities. Inclusionary processes are evoked whenever this message is effectively conveyed.*

## **PART FOUR**

### **CONCLUSIONS**

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The final two chapters in this thesis outline the main conclusions to be drawn from this small-scale qualitative study of social exclusion. Chapter 11 reflects on the relevance of the social model for understanding meanings of social exclusion and inclusion in the context of older people in care homes. Attention is paid in this chapter to the strengths and weaknesses of the model in light of the main findings from this study. The process of involving people with dementia in a research study like this is also reflected upon.

The final chapter in this thesis - Chapter 12 – discusses the implications this study has for theory, practice and policy in relation to both social exclusion and dementia studies. Discussion involves revisiting the research questions as set out in section 4.3 of this thesis and exploring the relationship between my initial objectives and the work carried out. The chapter summarises the essential elements of this thesis, and focuses in particular, on the essence of the experience of social exclusion. Discussion concludes with an evaluation of what I see to be the main drawbacks of this study and suggestions as to what further studies exclusion and dementia might investigate.



## **CHAPTER ELEVEN**

### **Reflections on the social model of disability**

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#### **11.1 Introduction**

The potential that the social model of disability has for understanding meanings of social exclusion to older people with dementia in care homes has been raised throughout this thesis. This chapter reflects on the relevance of this particular paradigm for understanding these meanings and for promoting the social inclusion of this group of people. The first part of the discussion is organised according to the three main areas of debate that tend to occupy disability theorists, namely: the general structure of the original model, particular the way that it is based on an either/or, medical/social approach to disability and so disavows any analysis of impairment; the methodological issues that researching disability raises; and thirdly, future conceptual directions that the model should take.

#### **11.2 General reflections on the social model**

In this opening section a number of general reflections are made about the social model of disability based on the findings of this small-scale study. Discussion begins by outlining the positive contributions that the model has made to my understanding of meanings of exclusion and inclusion. The least relevant or helpful areas of the model are then discussed and suggestions are made for how these might be developed. Discussion about the contribution that this study makes to the particular debate concerning 'impairment' is discussed in the subsection.

One of the most positive contributions that the model has made to my analysis of dementia as a disability is that it directed me to examine the full range and depth of barriers that an

older person with dementia living in a residential care home is likely to face. Up until now people in this type of situation have tended to be either medicalised or psychologized to such a degree that little analysis has been made of the wider political position that this group often find themselves; namely, one of low income, few civil rights and opportunities to participate in everyday life, particularly outside the immediate service environment. Therefore, a focus on the ‘sites and mechanisms of institutionalised oppression’ that an assessment of the social model of disability demands (Mulvany, 2000: 585) was what prompted the phenomenon of dementia to be uncharacteristically investigated as a political and social issue rather than as a purely medical or social-psychological one.<sup>38</sup>

The usefulness of exploring the issue of oppression in relation to this group was apparent in Chapter 6 when wider economic and social conditions and the impact that they have on people were explored. That discussion highlighted how institutionalised discrimination towards people with dementia can be. Recall how both the environmental health officer and social services inspector dispensed with certain standards and rights (such as talking with people and access to information) because people had dementia. Clearly it is not appropriate to generalise about the extent and nature of oppressive practices based on the findings of this *small-scale qualitative study*. *However, it is possible to contend that* individuals affected by the practices of these two professionals are part of a global ‘disadvantaged or marginalised constituency’, namely, disabled people, many of whom are also segregated and deprived of many of their rights (Shakespeare and Watson, 2001: 547). Having the social model of disability as an integral part of the conceptual framework for this study reveals the similarities between participants involved in this study and disabled people worldwide.

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<sup>38</sup> This point is revisited in section 11.3. of this thesis.

The social model of disability has brought to this study a heightened awareness of how formidable and endemic some of the barriers to social inclusion are for people with dementia. For instance, the lack of transportation that hindered some participants' access to the outside world is a notoriously common problem for people with a disability (Charlton, 1998). Similarly, Chapters 7 and 8 exposed the extent to which the organisations involved in this study sought to impose their own values and beliefs based on ideas of 'normalcy' in much the same way as traditional charities have done in respect of other disabled groups (Drake, 1996). Perhaps the best example though of how common the barriers are facing people with a disability is to consider the way that space was organised within the East Wing: people in the 'early stages' were accommodated downstairs and people in the 'advanced stages' were accommodated upstairs. The same segregation and ranking of people has occurred within other parts of the disability service. While, younger people with a disability have traditionally been ranked by care services according to degree of employability (Finkelstein, 1993), residents of the East Wing were essentially 'ranked' according to degree of communicability. The full gravity of the position that an older person with dementia in a residential care home might find him or herself in would not have been recognised or appreciated if it were not for the influence of the social model of disability.

In terms of the least relevant or helpful aspects of the social model of disability, at a basic level it can be argued that 'all social theories have limitations. None is a total explanation of reality' (Corker, 1999: 627). Thus, finding limitations in the model was inevitable. One of the least helpful aspects of the model was the lack of insight it gave into how people who were not young, politically aware and mentally strong should seek to gain more power for themselves and thereby change the status quo. People with a disability who were politically and mentally astute devised the model and so it was assumed that everybody affected by disability would eventually find their political consciousness (Charlton, 1998).

Given that the lack of propensity to complain amongst older people is widely noted in the literature, it may be that older people affected by disability require a different approach before they will ever take up their basic rights (Brooker, Nystrom and Segesten, 1994). As stated in Chapter 3 prescriptive accounts of how greater control should be achieved and who should instigate the process would seem to disable people affected by cognitive impairment still further.

The social model was also unable to help understand the different issues affecting older people. As well as not wanting to complain or speak out about services, older people, particularly those aged eighty-five years and over who are more likely to be frail and in poor health, may simply not want to change things, not at a political or societal level anyway. Recall how the laundry system was the main 'bugbear' for Mr. Smith, and Mrs. Wells could not understand why no one objected to having their medication at exactly the same time as people were eating breakfast. The types of changes these participants wanted to see were microcosmic compared to those envisaged by staunch exponents of the social model. Parsloe (1997) suggests that everyday choices are as, if not more important for this group of people in this particular situation than full scale political empowerment. It is difficult to explore these issues within the social model of disability, as the framework does not countenance the toning down of political empowerment (Oliver, 1996a).

Perhaps the most unhelpful aspect of this model was one which was once its strength - that is, the binary opposition between medical and social explanations of disability on which it is based. The representation of disabled people based on a binary model is misleading as it implies that peoples' problems can be neatly categorised and overcome given the right approach. The problem with this according to French (1993: 17) is that some of the most profound problems that some people with certain impairments face, are difficult if not impossible, to solve by social manipulation alone. This author bases her view on her

experiences of being visually impaired; there is little any one can do, she says, about some of the social problems that she encounters, such as not being able to recognise people, being nearly blinded when the sun comes out, and not being able to read or emit non-verbal cues correctly. Similarly, some of the problems that a few participants in this study faced could not be rectified simply through social action; for example, Mrs. Peters who got out of breath while talking; Mr. Smith, who found it increasingly difficult to retain information, and Mr. Brown who said that he had difficulty in recalling what people had just said to him. Exploration of this space in-between is essential for an inclusive conceptual framework to expand (Corker, 1999).

When the social model of disability was first conceived over twenty years ago this either/or approach to understanding disability proved invaluable in redressing the balance away from biomedicine in favor of social explanations of disability. The simple distinction between a medical or social approach to disability meant that non-disabled people had a better chance of understanding what it was that people with a disability had a problem with and exactly what it was they were striving to change (Oliver, 1996a). However, since then, not only have ideas about society changed but knowledge of the social world is no longer seen as something which is objective or fixed (Billington, Hockey and Strawbridge, 1998, Rosenhau, 1992). Also, paradigmatic shifts have been made in terms of both legislation and the way that disability is officially classified by WHO. Therefore, I would suggest that the binary opposition on which the model is based is no longer credible or necessary.

### **11.2.1            Consideration of the ‘impairment’ debate**

It was noted in Chapter 3 how there exists within disability studies a growing controversy surrounding the topic of impairment. This section reflects on this aspect of the model in more detail and considers the importance of the analysis of impairment based on the findings of this study.

A key observation made in this study was that because others cannot see the full extent and nature of a person's impairment, assumptions about what a person can and cannot do were made quite readily. Recall how intolerant Mr. Clarke of Encombe House was of other residents because he was convinced that 'there's nothing wrong with them'. Similarly, as far as Mrs. Wright was concerned there was no point in mixing with other residents whose 'minds have gone, or they are a bit dopey'. The sweeping generalisations these participants made about other residents reveal the type and level of misunderstanding that can abound in relation to people with dementia whose impairment is 'hidden'. Impairments which are not visible and which are also unstable and unpredictable, like dementia, have caused some protagonists of the social model to concede on the issue of impairment and to say that in such circumstances analysis of impairment is justified (Barnes, 1996: quoted in Corker, 1999). I would strongly concur with this view on the basis of this study.

It is argued that 'oppression and prejudice become embodied and become part of the experience of everyday life' (Paterson and Hughes, 1999: 605). The main insight this study gained from analysing peoples' subjective experiences of impairment was that people were differently affected by, and *responded differently to, cognitive impairment*. The different affects that cognitive impairment had on people were often difficult to disentangle from the other factors in a person's life. For example, Mr. Brown was reported to have headaches, and indeed during our first interview he described what they were like: fleeting and localized. Mr Brown's headaches may have been symptomatic of his dementia or the noisy environment in which he was living; alternatively this eighty-four year old man could have been hypertensive or in need of an eyesight examination. Whatever the cause of Mr. Brown's headaches, including his experience of them in an assessment of the social model not only highlighted how difficult it might be to identify what the barriers to social

inclusion are for any one person, but also the possibility that an older person will deal with and respond to bodily change very differently from the next (Tulle-Winton, 2000).

Close scrutiny of individual experiences of dementia clearly provides valuable insight into how people affected deal with the condition. In section 8.4 of this thesis Mr. Smith's adaptive strategy to loss and impairment was discussed. This involved him telling himself that he had no choice but to relent, he said, 'up here tells me that I have got to put up with it. And that is what I have done'. In contrast, at eighty-years old Mrs. Clark remained hopeful – a state of mind which is considered by Barton (2001) as a prerequisite for radical change - that the chronic fatigue which she experienced would soon pass. Nuggets of insight like this into the different ways that people with dementia deal with the affects of impairment are crucial in raising awareness of dementia as a disability.

The disabling aspects of dementia are very different from those facing people with a physical disability. Discussions in Chapter 2 and observations made in Chapters 6 and 8 reveal how one of the major barriers that people with a dementia continue to face is the propensity to medicalise dementia (Bond, 1992). For example, if a person has a mental health diagnosis (such as dementia) displays of anger or dissatisfaction are more likely to be viewed as symptomatic of a person's psychopathology (Sayce, 2000). This certainly seemed to be the case for Mrs. Green as when she asked her husband for a divorce he put the request down to her 'dementia' rather than his behaviour. While much work has been done within disability studies to dismantle this particular barrier, it focuses almost exclusively on physical disability and as such does not help people with dementia. The large and growing body of knowledge on the representation of people with a disability is a case in point (Hevey, 1993, Campbell and Oliver, ed., 1997). This literature offers no insight into how dementia is represented in the public sphere (McColgan, Valentine and Downs, 2000). Because of the neglect by disability theorists into the phenomenon of

dementia, and indeed mental ill health generally, the issue of impairment is considered a pressing one (Mulvany, 2000).

### **11.3 Future research directions: disability studies**

The implications this study has for future research directions within disability studies are far reaching. At a fundamental level it requires modern disability theorists to think again about drawing on a conceptual framework, namely the social model, which advocates the idea that ‘one size fits all’. Future research directions within disability studies should therefore be considered in conjunction with the future of the model itself.

Based on the work of this small-scale qualitative study I see disability studies needing to concentrate on three key areas of conceptual development. First, given the lack of understanding and high levels of intolerance that persist in relation to mental health conditions like dementia, there is clearly scope for considerable work on why some impairments should be less socially acceptable than others. As Tregaskis (2002: 467) says, disability studies should seek to establish ‘theory-level responses to problems like the persistence of disabling attitudes’. In this way, not only will greater understanding be gleaned about the stigma of dementia but also, more creative and comprehensive solutions to exclusion might be found. For instance, considerable work has been achieved within disability studies about the way that people with a disability are represented in modern society as tragic and pitiful people (Hevey, 1993). The same level and type of focus should now be directed to people with dementia <sup>39</sup>

Second, the study highlighted how it is not only people with physical disabilities who are susceptible to normative discourses such as ‘independence’, but also older people with dementia in residential care homes are at risk of stigmatisation because they are unable to

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<sup>39</sup> Further examples are given in section 8.6.



do everything for themselves. However, the alternative definition of independence advanced by disability theorists –that is, to be in control of your own life (Oliver, 1996a) fails to improve the position of people who are cognitively impaired either. What is needed within disability studies is further deconstruction of terms like, ‘independence’ and ‘dependence’ and greater consideration of the mutual linkages that exist between people and within environmental contexts (Twine, 1994). Theoretical developments of this nature would do well to draw on work by Bond (1999) and Nolan et al. (2002) who all advance the notion of ‘interdependence’ and the idea of ‘intersubjectivity’ of the kind experienced by Mr. Smith and his key worker when they danced together.

Third, and perhaps most critically, the dominant position of the social model of disability in modern disability studies must be urgently questioned; a request that has already been made by established researchers in the field (Marks, 1999a, Fawcett, 2000). From the perspective of this study, while the framework clearly has some relevance in understanding and improving the lives of people who are segregated because of impairment, the model is ultimately too simplistic and unyielding in its approach to disability to appreciate the minutia of factors influencing the social exclusion and inclusion of older people with dementia in residential care. A more holistic understanding of this group of people in this situation is more likely to arise by drawing on a combination of models and theories rather than relying on a single social model of disability; such an approach would include not only social understandings of dementia, ageing and disability but also biomedical explanations of dementia as a biological and neurological process. Only by doing this will the complete range of barriers to social inclusion ever be properly identified and rectified.

#### **11.4 Reflections on researching dementia as a disability**

Studies of dementia that directly involve people affected are still relatively rare. This section considers the implications of this from the perspective of the social model of disability. It then outlines some of the methodological insights that might be gained from this small-scale qualitative study of social exclusion and dementia.

Chapter 2 explained how much of the voluminous literature on residential care has not dealt with the experiences of people with dementia. This is because people with dementia are often seen and treated by researchers as a homogenous group incapable of contributing to a research study (Goldsmith, 1996). Even enlightened authors on the subject of mental health make the assumption that it is extremely hard to access directly the experience of those who have dementia (Barnes and Bowl, 2001). Consequently, people affected by this condition have become a notably 'silent and excluded' voice in social research (Wilkinson, 2001). However, the generally accepted view within the field of dementia studies is that it is possible to have constructive and meaningful conversations with the majority of people affected (Braudy Harris, 2001).

Most researchers within the field of dementia care agree that there is a need to find more creative ways of engaging services users in debates about the quality of care services (Stalker, Gilleard and Downs, 1999, Barnett, 2000, Woods, 2001, Reid, Ryan and Enderby, 2001). The need is even greater when one considers the extent to which qualitative research involving people with dementia is slowly beginning to expand. To date much of the concern about research has focused on either ethical issues such as gaining informed consent (McCall Smith and Nichols, 1992; Agarwal, 1996; Crossan and McColgan, 1999; Bartlett and Martin, 2001) or interviewing techniques and styles (McIssac, 1995; Fisk and Wigley, 2000). While ethical and communication issues are undoubtedly critical to consider, I would suggest there are equally important questions to ask about the politics of

dementia care research. Not least whether the methodological paradigm in which dementia care research is currently taking shape is oppressive and disabling for an individual with dementia.

Protagonists of the social model, many of who are themselves physically disabled, concern themselves with questions about the methodological paradigm which normally shapes disability research (Oliver, 1993, Stone and Priestly, 1996, Shakespeare, 1996a). All these researchers believe that the process of researching disablement has the potential seriously to oppress and undermine the agency of individuals with impairment. Their view is based on a set of assumptions about how research is conducted – that is, by non-disabled researchers seeing disability as a medical phenomenon and thus treating participants as ‘objects of intervention’ rather than as equal partners (Campbell Brown, 2001: 157). However, this perception of how disability is researched is just that. There is no empirical evidence to support such claims and it is difficult to believe that *all* disability research is conducted in this way (Bury, 1996). The manner in which disability is researched is clearly a contested issue.

Within dementia studies debates are also emerging about the best way of involving people with dementia in research and care audits. Given the relative newness of this area of social enquiry there is little methodological guidance to either inform this debate or to guide researchers (Reid, Ryan and Enderby, 2001). The approach to research that Oliver (1996a) envisages is one based on the notions of empowerment and reciprocity. This involves people with disabilities being involved in all aspects of the research process, from setting the research agenda so that issues which concern people with disabilities (rather than the non-disabled research community) are investigated, to deciding how research findings are disseminated. This ‘emancipatory model’ of research was recently adopted by The Alzheimer’s Society. This charitable body is leading the way in terms of how to conduct

research into dementia by improving ways in which it involves more people affected and their carers in its work, structure and decisions it makes (Litherland, 2000). However, dementia studies which are not funded by the Alzheimer's Society are not obliged to include with people with dementia to this degree neither are they bound by the research principles of the emancipatory model. Therefore, there remains considerable scope for improving research paradigms for dementia research.

According to Bond and Corner (2001) the main methodological issue to consider in the context of dementia care research is not what 'unique challenges' this research population poses but the exposure it gives to the complexities of researching the social world generally. In the process of accessing and interviewing older people with dementia for this study, a number of methodological complexities arose, which would be of interest to researchers involved in the study of any vulnerable groups (such as children, people with learning disabilities or long-stay hospital patients). The first was a practical issue relating to the budgeting and timeframe of this study and the larger project of which it was part. Part of the budget was set aside for travel expenses: it was estimated in the project proposal that 4% of the budget would be required to facilitate travel to and from study sites, and six months were allocated for the collection of data from individuals without dementia, individuals with dementia and their families. In common with the majority of qualitative research projects, these proposals were based on an 'educated guess' about how much money and time would be needed to carry out the work. On reflection, I do not feel that enough time was given in the research design to getting to know participants.

Booth and Booth (1996) point out the time that researchers allow for data collection is often what is appropriate to funding bodies and research councils rather how much is actually needed to sensitively explore peoples' experiences. Especially, if like Mr. Brown and Mr. Smith an individual relishes the opportunity to talk, or, maybe like Mrs. Clarke

and Mrs. Green are mistrustful of the interviewer's agenda and motives. The time-consuming element of qualitative interviewing is traditionally seen as the major weakness of this method (Denscombe, 1998). Given that the challenge is for us who do not have dementia to become better able to understand those who do (Cox, 1998: 9), I suggest that the time consuming element of qualitative interviewing is a strength (rather than a weakness) which must be exploited in this area of research.

A second methodological complexity, which relates to the issues of time and trust, and in particular to the impact these have on informed consent, was alluded to in section 10.4 of this thesis. In that discussion it was revealed how uncomfortable the interview process was for some people involved in this study. For example, Mrs. Clarke seemed particularly unhappy about the use of a tape recorder:

Is it taping everything I say?

Yes.

I had better be careful then.

*It is only me and (another researcher) will listen to it nobody else will view it.*

When you take it away and places they can.

*No because I won't let them.*

Well that is your tale isn't it ..

*(interview takes place).*

*I think we will finish today but can I come back and see you another time?*

Don't bring that darn thing; switch it off

(Mrs. Clarke, age 80, Lulworth Court).

In hindsight, one could say that the reason for the discomfort that this woman seemingly experienced was because insufficient time had been spent getting to know her and building trusting relations, but speaking more honestly, and with the strong views of Stone and Priestley (1996) very much in mind, I think it was because, as young, able minded researchers we were in a position to take advantage of her vulnerabilities.

Further evidence of the balance not quite being struck right between intrusion and data collection (Braudy Harris ed. 2002) was evident in the interview transcript of Mrs. Green. At various times throughout the interview this participant sought more information about the purpose of the research. For instance, she asked:

What are you doing this in aid of?

*Oxford Brookes University. It is a project. Do you remember I gave you the leaflet?*

*Yes. Is there anything else you want to ask me?*

I don't think so. You can't help wondering in a case like this - one can't help wondering what you are trying to get out, can you understand what I mean?

(Mrs. Green, age 77, Durlston Court).

Having just been asked a question about whether she had any friends in the home, Mrs. Green was compelled to ask about what and whom the research was for – maybe the question seemed irrelevant to her. Issues of reciprocity and benevolence also concern many within the field of disability studies (Shakespeare, 1996b). This is because of the amount of research that is conducted which is considered of little or no benefit to those who are disabled (Oliver, 1993). While these issues can be raised in a PhD thesis, I think it is important that researchers in this field generally, are more open and honest about ethical

practices, particularly when they are unethical (Lee-Treweek and Linkogle, 2000). For example, when interviewers fail to achieve a balance between intrusion and necessary data collection (Braudy Harris, 2002). Otherwise, there is a danger that aspects of dementia care research not only become irrelevant to people affected and their carers, but also that the experience becomes an oppressive and disabling one.

### **11.5 Implications for practice**

Defining dementia as a disability raises a number of practical implications for the strategic development and delivery of dementia care services. This sections outlines three based on the observations from this small-scale study.

First, people with dementia are legally protected by the Disability Discriminations Act (1995) and so to treat those affected less favourably is not only bad practice it is also unlawful. This is to say people with dementia have a right to the same goods, services and facilities as other service users and so those affected should not be excluded from something or from going somewhere simply on the grounds of their dementia. As new disability legislation is rolled out service providers need to be made aware of the possible implications *this has on the way that activities are resourced, planned and delivered*.

A second implication of thinking about dementia as a disability is that the collective identity of those affected is both emphasised and regarded as a potential source of strength. It may seem counter-intuitive within dementia care to see people as being part of a 'group' rather than as individuals with unique needs. But to concentrate on what people with dementia have in common (such as a lack of alternatives to institutional care) and to focus on the barriers that face *all* people with dementia (such as cognitive bias in wider society) then maybe those affected would have increased opportunities to empower themselves. In practice, this would mean providing more opportunities for people with dementia to talk

about their difficulties to others, who might share the experience (Clare, 2002); ensuring the layout of communal areas is conducive to interaction (find ref); providing people with topic-based information such as advice and advocacy services and support groups (Joseph Rowntree Foundation, 2003); finally, and perhaps most importantly within the residential care sector, ensuring that those involved in the planning and delivery of activities are aware of the value of simply talking with people and facilitating conversations between people.

A third and final implication for practice relates to how well people with dementia are supported through transitional phases of care. This study has shed some light on the different meanings that people with dementia attach to moving into residential care. For Mr. Brown the move seemed to signify his working class status, whereas Mrs Dryden saw the move as representing her need to rest and convalesce. Or, indeed the extent to which residents with dementia regard the institution they are living in as 'home'. Disability writers remind us of the dangers of spatial segregation; of placing people with disabilities apart from the rest of society (Kitchen, 1998) and particularly the risk of people internalising feelings of anger and resentment when this happens (Marks, 2001). It is imperative therefore that people with dementia have an opportunity for extended meaningful conversation, particularly during times of transition. These conversations would not necessarily have to be with care staff, as opportunities could be created and sustained in partnership with existing residents for example. Finally, whilst there are resource implications of these three suggestions, the disablement of people with dementia relates to not only the quality of care, but also the politics of disablement and exclusion.



## **11.6 Summary**

This chapter has reflected on the applicability of the social model of disability to understanding and improving the position of older people with dementia in residential care. Discussion has focused on the positive and negative contributions that the social model of disability made to this analysis of dementia. In addition, the chapter focused on an aspect of disability which does not feature in the social model but which most critics of it are particularly concerned about, namely impairment. The main conclusion to be drawn about the relevance of the social model of disability is that it is very helpful in raising awareness, of and seeking to understand, the oppressed position that an older person with dementia in a residential care home might find him or herself in. However, it offers little guidance as to how to then improve their position.

## **CHAPTER TWELVE**

### **Implications for theory, policy and practice**

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#### **12.1 Introduction**

This final chapter in this thesis is concerned with the implications this study has for theory, practice and policy. The chapter guides the reader through the essential elements of the argument made in this thesis, and that is that, the core meaning of exclusion for older people with dementia in care homes is loss of identity. Discussion revisits the literature reviewed in Chapters 2 and 3 and in light of the main findings of this study suggests ways in which meanings of social exclusion in relation to older people with dementia in residential care services might be further addressed and researched. Given the qualitative nature of the evidential base on which this discussion draws, the generalisations which are made in this concluding chapter are designed to generate further theorising about people in this situation (as opposed to claiming they are representative of other people in the same situation) (Ritchie and Lewis, 2001). The chapter is broadly organised into four key sections.

The first section focuses on the relationship between the work done in this study and the central research question it set about the meaning of social exclusion. As well as clarifying the meaning of social exclusion, the essence of the experience of this phenomenon is also elucidated. The utility of this concept in relation to older adults with dementia in residential care homes is then considered. This leads to a discussion about the implications this study has for a social theory of dementia, a discussion that draws heavily on sociological insights concerning the concepts of self and agency. The policy implications of the study are then outlined, and in particular, how people with dementia might be more

involved at this level of service planning and development. Lastly, the limitations of the study are considered, before the chapter finally concludes by looking ahead to the type of research that might follow from this study.

## **12.2. Contribution to social exclusion/inclusion debate**

The contributions this study makes to understanding what social exclusion means are argued to be fundamental. In seeking to understand the meaning of social exclusion from the perspective of those deemed to experience it, the study has shown how key, identity is to understanding what this concept means: participation in mainstream activities (such as work or housework) is so important because it provides people with a social identity. The main implication of making explicit this definitional aspect of social exclusion is that it makes other routes to inclusion, besides work, more apparent.

In the context of this phenomenological type study, the essence of the experience of social exclusion is argued to be the loss of social identity. Chapter 6 reported on the ways in which wider social and economic circumstances (such as high employment) reduced some participants' *opportunities to do mainstream things (such as shopping)* and thereby create the conditions for experiences of exclusion. Recall how in section 6.2 of this thesis Mrs. Wright described the sense of exclusion a loss of income and property rights can evoke. Chapters 7 and 8 explored how certain organisational influences created the conditions for spatial and cultural experiences of exclusion. For example, in section 7.2 of this thesis, data pertaining to 'not going out enough' was interpreted as evidence of participants' being pinned to their locality, and in section 8.4 intolerant attitudes towards those with dementia were interpreted as a means for the 'excluder' to maintain their own sense of identity. Subjective experiences of social exclusion were explored in Chapters 9 and 10 through the narratives of participants affected by dementia. In these discussions, the mental and

physical experience of social exclusion was discussed. For instance, in section 9.4 of this thesis a common experience amongst some participants was shown to be the internalisation of ageist discourse.

Understanding the meaning of social exclusion from the perspective of those labelled 'excluded' highlights how restrictive and unhelpful official definitions of social exclusion are. Government describes the process of exclusion as 'individuals or communities, suffering from a combination of problems' as though every single aspect of the situation a person or community is in is dreadful, and is experienced as such. In uncovering the importance of identity, this study has shown that this is not the case, as whenever there are opportunities for people to be the sort of person they perceive themselves to be inclusionary processes are evoked. Take for example the experience of Mr. Smith who did not really want to move into Encombe House. He said his sons 'coaxed him' to move in, Even so, this participant said how 'happy' he was and that he 'was glad he did', possibly because the situation gave him more opportunity to be the gregarious man that he was. Other studies have found that older people find the experience of care home life better than they expected it to be (Allen, Hogg and Peace, 1992) suggesting that moving into a care home is not necessarily a problem or cause of exclusion in itself.

I have argued in this thesis that a definition based on a binary opposition, like exclusion and inclusion, is wholly unhelpful given the complexities and fluidity of peoples' lives. This raises questions about the utility of a concept like social exclusion for understanding the situation of older people with dementia in residential care homes. Like O'Connor and Lewis (1999) I have concerns that the notion of social exclusion could potentially add to the stigma of an already stigmatised group of people living in an already stigmatised form of housing. Indeed, the research proposal was written based on the assumption that exclusionary processes would inevitably be found. While the study sought to identify

influential factors in both the exclusion *and inclusion* of people in this situation, because of the preoccupation the concept has with what people lack (rather than what they have) this has necessarily been the primary focus of this study. Given the conclusions reached in Chapter ten about the ability of some individuals to resist exclusionary processes, and the possibility that others are not even affected by them, the value of always assuming that people are ‘missing out’ because of the situation they are in is an unhelpful one. The implication of this for social exclusion as a working concept is that it is in danger of adding to the problems that an individual or community already has.

Based on the findings of this study, it is more constructive to think of individuals and communities as being on an inclusion trajectory: on a path with some opportunity for ‘identity work’. The concept of exclusion does helpfully highlight how important it is to consider how single problems do combine (such as negative stereotyping and poor health status) and derail people from this track. As a small-scale qualitative study in search of depth of understanding, this work has managed to investigate how the interplay of such problems is both created and experienced amongst a sample group of older adults with dementia in residential care homes. A key conclusion to be drawn in this respect is that some individuals are under stronger influences than others. Take for example a narrative common to both Mrs. Dorking, aged 87 of Durlston Court, Mrs. Dunn, age 93 of Encombe House and Mrs. Clarke, age 80 of Lulworth Court. Each of these women was cognitively impaired and living in a residential care home. However, it was the internalisation of dominant discourses about older people being a burden on society that bound the experiences of these three women together. Identifying this influence resonates with the well-theorised view that women feel the social pressures to conform to appropriate body images and behaviour more keenly than men (De Beauvoir, 1988; Vincent, 1995).

Exploring how people feel about both themselves and the home in which they lived revealed another definitional aspect of social exclusion often overlooked in large-scale studies. That is how differently people experience the same place. Chapter 7 analysed data in relation to this issue and showed how organisational constructs of 'home' simplified the experience of living in this type of residence. For instance, brochures portrayed care home life as a 'home from home' and the staff within it constantly buoyant. In contrast, participants living in a care home created a much more complex picture of the experience. Some participants, for example, such as Mrs. Housel and Mr. Smith, clearly enjoyed living in a care home, others, like Mr. Brown seemed to be more ambivalent; a few others expressed a strong desire to return to their own house. Interpretations of why some older people find it more difficult than others to make transition to residential care home life can be found in the literature. These usually revolve around practices issues such as whether or not admission was planned or unplanned (Wilson, 1997); level of relative involvement (Davies, 2002) or the extent to which the individual was involved in the decision (Hockey, 1991).

Investigating the relationship between wider social divisions (such as those based on type of residence) and psychological processes of *exclusion also makes a fundamental* contribution to the study of social exclusion. In finding out how people actually respond to and deal with the problems that they face (*as opposed to simply quantifying the extent of the problem*), this study has shed significant light on a relatively uncharted aspect of social exclusion, that of hidden resistance. The range of strategies that some people with dementia taking part in this study used to preserve a sense of self-identity were outlined in Chapter Ten. The capacity of these individuals, who were not only cognitively (and some also physically) impaired *but aged as well, to challenge exclusionary processes*, particularly those relating to power dynamics, suggests that even the toughest forms of marginalisation can be reversed in some way. In addition, given the subtlety of resistive

methods used (for example, the ‘bath joke’ made by Mrs. Clarke of Lulworth Court) a conclusion from this study would be that exclusion is indeed a concept that requires the kind of sensitive methodological approach that some researchers call for.

### **12.3. Contribution to dementia studies**

This study is unusual in that it has undertaken a sociological investigation of dementia. Arguably, this has been the most fundamental and significant contribution this study has made to dementia studies. Thinking sociologically about dementia in this study has meant that more is now known about the relationship between social divisions and micro processes in relation to people affected by this condition. This section summarises what the main conclusions are in this respect, and what future research ought to follow as a result of them.

The gap in knowledge about the politics of dementia care was highlighted in section 2.3.3. of this thesis. This study has started to address that gap by using politically laden concepts such as exclusion and oppression to explore the experiences of a sample group of older people with dementia living in care homes. A basic conclusion to be drawn from this part of the work is the awareness that some participants had of their lack of rights as both consumers and as citizens. For example, Mr. Brown of Encombe House, did not seem to be satisfied with the explanation he said he had been given by staff for why the front door should be constantly locked; neither did he seem to feel that he was getting value for money given the poor standards of care, which he considered characteristic of staff/service user interactions. Similarly, Mr. Brown having expressed dissatisfaction with the laundry system did not wish to complain about it; maybe because, like others in Encombe House, he feared being excluded from the home as a result. The rights of people with dementia as consumers of services (Fisk and Wigley, 2000; Barnett, 2000) and as social research participants generally (see Wilkinson, 2001) is increasingly being recognised. However,

this study concludes that further research is needed into how poor consumer experiences affect people with dementia, and in particular, whether or not it leads to a personal sense of injustice.

The wider point to be made here is that dementia is clearly a political as well as a biological and social issue. People affected are disempowered, and empowered, by not only by care practices but also by much wider cultural influences. This study has reinforced the view that many of these relate to social constructions of dementia (Harding and Palfrey, 1997; Adams, 1998; Adams and Bartlett. 2003) and of age (Townsend, 1981; Vincent, 2000). However, the study also highlights how other more universally disabling processes also play a part. For example, public attitudes to mental ill health, and intolerance towards people who are unable to do or think about things for themselves may explain why Mrs. Green responded in the way that she did in her interview.

Mrs. Green's occasional annoyance with the interviewer suggested an awareness of a form of social exclusion, namely stigmatisation, which would damage the social self and 'spoil self-identity' (Twine, 1994: 11). The role of stigma in the lives of people with mental health problems is well explored outside dementia studies (Sayce, 2000). However, this study and that by Proctor (2001) are unusual in that they have used the concept to understand older peoples' experiences of cognitive impairment. More empirical work obviously needs to be done on the influence of stigma in the lives of people with dementia (Bond, 1999).

Dementia has mainly been conceptualised apolitically on the level of intersubjective experience. Given the extent to which some people with dementia involved in this study faced the same barriers as affect disabled people worldwide (such as lack of transport and poorly resourced services) I would argue that now is the time to think beyond the care



setting in dementia studies. This study suggests that as a discipline, dementia studies needs to consider more the impact of other fundamental social structures such as gender, class and ethnicity on the lives of people with dementia. For example, to my knowledge there have been no studies comparing men and women's experiences of dementia; nor has there been any substantive investigation into class or ethnic issues (Cantley, 2001).

Another contribution this study makes to dementia studies is to the debate about a person centered paradigm. The concerns that some researchers currently have about the individualistic approach, which is favoured in dementia care, were discussed in Chapter 2. Literature reviewed in Chapter 3 revealed how advanced these discussions are within disability studies. Some of the observations made in this study echo these concerns and show how integral relationships are to the continuum of self. As Proctor (2001) and I found an overriding theme of interviews with participants was relationships; the relationships that individuals had with care staff, with other residents, with the interviewer and with the place in which they lived were clearly influential in engendering feelings of exclusion or inclusion. However, this study identified another type of relationship, not so far considered in the debate about person centered care, and that is that the relationship that people have with themselves. Analysis in section 10.4 of this thesis of the conversations that people with dementia had in their heads, demonstrated how important this relationship is to identity maintenance; it allowed Mr. Smith to mentally manage the affects of his impairment, and Mr. Brown to maintain a sense of control over his situation. A further example of the importance of understanding the nature of peoples' relationship with their self was given when some female participants spoke of the biological cues of ageing revealing how embodied oppression can be. Clearly there is a great deal more work that still needs to be done.

## 12.4 Policy implications

A key policy question that ultimately remains unanswered in dementia studies is whether older people with dementia should be accommodated with other older people or whether a 'separatist' policy should be adopted (Meacher, 1972). Finding the best way forward in terms of finding housing solutions for older people with dementia in need of long-term intensive help and support is currently high on the Government agenda. In this section, conclusions are drawn about the main factors which policy makers need to consider.

According to Macdonald and Denning (2002), the first step is for policy makers to be more honest about the extent and nature of cognitive impairment in care homes. Basing their view on prevalence rates, these authors conclude that older people with cognitive impairment make up the majority of people using residential services. Therefore, they argue that specialist homes should be provided for people *without* significant cognitive impairment rather than, as is commonly the case, for those who are cognitively impaired. This view is a highly radical one but when applied to some of the individual situation encountered in this study, planners and policy makers might be advised to explore. For example, if mainstream homes *were* for older people with dementia then someone like Mr. Brown would perhaps not have to move away from his hometown, as the local authority home would be more able and resourced to accommodate his needs. The sense of isolation and confinement that Mrs. Clarke expressed was also compounded by the rural location of the home suggesting that policy makers should be giving even greater consideration to the emotional impact of locality on people with dementia.

The claim that the cultural organisation of spaces has the power to convey messages about the status of a group of people has been discussed and evidenced in this thesis. If the residential care home sector were to treat people who are *not* cognitively impaired as different, and provide 'specialist facilities' for them rather than for people with dementia,

they would have more choice about whom they wish to live with (Dalley, 2002). Equally, it would emit positive signals about the status of older people with dementia as a client group, as they would be for whom mainstream services were intended. Obviously these changes would require considerable strategic planning and joined up thinking on the part of other providers including housing and broader social care services. Unfortunately, the coherent policy approach that this requires is not yet in place (Cantley, 2001).

In the meantime, policy makers (and practitioners) need to find ways of engendering and supporting a culture of acceptance rather than intolerance amongst service users in residential care homes. This might mean basing policy and developing standards on the information and training needs of *all* groups. Care workers' education and support needs have been extensively discussed in relation to older people with difficulties related to dementia (Cox, 2001; Brooker, 2003a). However, an education need that is not identified in the literature is that of inspectors. So, rather than concentrating solely on the training needs of staff groups, an organisation might also be expected to meet the information needs of residents. Although, as a survey by the Joseph Rowntree Foundation (2003) recently found, the lack of access to information that older people generally have in relation to health related topics is a cause for concern. Given how disturbingly high levels of intolerance were amongst some people taking part in this study, an information giving approach might help alleviate this particular exclusionary factor.

A further implication of this study relates to the capacity of people with dementia to comment on the quality of services they receive. Dementia is clearly a formidable 'mental obstacle' to people becoming active participants in policy and service planning processes (Walker, 1999). However, this study concludes, as many others have, that people with dementia are able, and more importantly are in the best position to inform the policy context and to reflect on what changes need to be made at this level of service planning

(see Wilkinson, 2001). Unless efforts are made to include people who are cognitively impaired there is a danger that as the demand for new improved 'third age' housing increases, the opinions and 'needs of the poorest, least articulate and most disadvantaged' continue to be overlooked (Hanson, 2001: 50).

### **12.5 Limitations of the study**

As with any qualitative study, there are a number of limitations to be highlighted and discussed. This section reflects on the main areas of weakness of this study, including, the size and profile of the sample groups, and the primary method of data collection.

Discussion highlights how some of these limitations were partly due to the study's involvement with the larger project. This leads to a discussion about the implications of doing a PhD alongside another project.

The size and profile of the sample groups, particularly those involving people living in care homes, is a recognized limitation of this study. The main reason for this is because of the relatively small numbers of people who participated at each stage. recommends that small scale qualitative studies of this kind aim to involve participants, excluding members of the focus groups, this study interviewed a total of people. The profile of sample groups was also a limitation of this study, as there was too little diversity to explore the varying influences of different factors (Ritchie and Lewis, 2003). For example, in terms of ethnicity, every single participant was white, and with the exception of Mr. Smith, who was Welsh, all participants were English.<sup>40</sup>. One explanation for the insufficient diversity in the sample population was that it was biased by the recruitment of people selected by care home managers. Another would be that we did not recruit enough people. Whatever the explanation a consequence of the small number of individual participants and study sites was that meaningful comparisons could not be made between groups and settings.

Chapter 5 explained how ethics approval depended on prospective participants being approached by the care home manager first rather than the interviewers. This meant that people were nominated who care home managers said 'like to chat'. While this is undoubtedly a helpful quality in an interviewee, it did raise concerns (certainly for me) that other people in the care home, who for whatever reason preferred 'not to chat' were unnecessarily excluded from taking part in the study. Consequently, the possibility remains that care home life is characterised by layers of exclusion, as care staff might routinely think of some residents as being more able and willing to participate in a mainstream activities than others.

A second major limitation of the study relates to the methods of data collection that were used. While the study aimed to adopt an eclectic approach to data collection it did rely heavily on the interview method and narrative data. According to Silverman (1997) this is a common tendency for social researchers as oral accounts are taken to be 'the best' source of information about social phenomenon. However, in the context of this investigation it meant that people with dementia who were perhaps most likely to be affected by exclusionary processes, namely those with diminishing or no verbal skills, were excluded from this study.<sup>41</sup> I did consider using dementia care mapping as a means of gathering observational data.<sup>42</sup> However, as some of the assumptions underlying this tool may not be applicable to all individuals it was discounted<sup>43</sup>. On reflection, given that a subgroup of

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<sup>40</sup> The most likely explanation for lack of ethnic diversity is the location of study sites which were all in small towns or suburbs of southeast England

<sup>41</sup> The larger project was deliberately designed to only include people with dementia who were able to verbally communicate.

<sup>42</sup> Dementia Care Mapping is an observation evaluation tool to assess the well being of individuals in formal care settings (Cantley, ed. 2001: 319)

<sup>43</sup> As Bamford and Bruce (2000: 547) point out the assumption that it is better for a person to be engaged rather than disengaged, and that interacting with people promotes well-being may not be applicable to all individuals.

people with dementia was identified in one or two of the study sites, the study would have benefited from a greater variety of qualitative data as well as a greater variety of people.

A final limitation of the study was also its strength, and that was its integral involvement with the larger project. Doing a PhD can be an isolating and difficult process (Phillips, 1987); however, carrying out this work as part of a small project team meant that this was not the experience I had. As the project team comprised of experts in the fields of gerontology and dementia studies, I was well supported and supervised throughout the life of the larger project. Moreover, as a team of researchers we were in a position to share ideas and tasks and thereby maximise the relatively short amount of time that we had to obtain ethics approval, access study sites and participants, and collect data. However, I found that one of the main problems of doing a PhD as part of a larger project is that it delays and complicates the development of the conceptual framework for your own thesis. For the first two years of my PhD I was working on a project which shared my concerns about older adults with dementia in care homes but which did not fully reflect my interests in exclusionary processes and disabling practices. I believe this is why certain data (such as income levels, health status and access to services) was not more systematically collected, and why relatively few people with dementia were involved in the study. With more of this type of data I think other forms of exclusion might have been found. Furthermore, with hindsight, I think more probing questions might have been asked of other participants to gain a more comprehensive picture of tolerance levels and stigmatising process in integrated care homes, as this, I think, is the key to understanding oppression in this particular type of residence.

## 12.6 Summary

In summary, the study has identified and explored a range of social, psychological, economic, organisational and biological factors shaping meanings of social exclusion and inclusion. The main argument underlying these discussions has been that the core meaning of social exclusion is loss of identity, which, in the context of this study, individuals affected by dementia had the capacity to recognise and creativity to counter.

The countering of exclusionary processes in this way by this group of people is a central finding of this study. The finding is important because it adds further weight to claims made by those within the field of dementia studies that the self remains intact despite the disease process (Sabat, 2001). The argument is also important as it supports more fundamental claims made by sociologists that the sense of self is inextricably linked with social and cultural formations (Burkitt, 1991; Twine, 1994; Jenkins, 1996). In the context of this study, the type of social and cultural formations found to be integral to this relationship were those related to ageist discourse and disabling language and attitudes. Recall, for example, what a disabling effect ageism was said to apparently have on Mrs. Clarke's sense of self.

A recurrent theme of this thesis has been the way in which individuals affected by dementia interact with the world around them, as they learn to live with the biological and social realities of their condition and the ageing process. These discussions have evidenced how the self is constituted and reconstituted in the context of someone with a dementing condition. For example, in section 8.4 of this thesis Mr. Smith's adaptive strategy to loss and impairment was discussed. This involved him telling himself that he had no choice but to surrender to changes within his own self, he said, 'up here tells me that I have got to put up with it. And that is what I have done'. The insight this study brings into understanding the agency of people with dementia is another important element of this thesis. This is

because it challenges the view of people with a disability (including those with dementia) which remains dominant in mainstream society, and that is that people with a disability are devoid of power and self competence (Oliver, 1996a).

In evidencing the agency of participants with dementia, the study has also showed how social identities are constructed in the context of different spaces. Take the case of Mrs. Green for example. The various accounts of Mrs. Green's behaviour, from not only herself but also the manager of the care home and her husband clearly demonstrated how social identities can be constructed (and co-constructed) in the context of different spaces. In the interview, Mrs. Green seemed keen to present herself as someone with identities other than 'patient', including a wife, mother and businesswomen. The care worker's accounts of how this participant used different spaces within the care home was seen by me as a way for her to express these non-dementia identities. In contrast, her husband, perhaps needing to justify why he had admitted her to a specialist care home – used the space that she was in to *confirm* what he was saying about her status as a 'mental patient'.

The role of space in the construction of social identities was also clearly evidenced in sections 7.2 and 7.3 of this thesis. In the context of this study, I believe these discussions are crucial to understanding the level and type of individual activity that can go in within the dialectical relationship between self and society (Burkitt, 1991).

For example, it was argued in these sections that the locality of a care home and the configuration of spaces within it have the potential to send both positive and negative messages to people about their 'place' in the social world. Recall how pleased Mr. and Mrs. Spinks claimed to be because of the amount of private space they had, but how bewildered Mr. Brown said he was by the 'twisting and turns' of the corridors. These findings add further substance to current sociological debates about the importance of



place and meaning of 'home' in contemporary society (Reed, Roskell Payton, and Bond, 1998; Siegrist, 2000).

In conclusion, this thesis has added to a wide range of cognate debates. Sociological, psychological and biological theories and concepts have been brought together in one single study to analyse the situation of older adults with dementia in residential care homes. The main conclusion to be drawn from this unusual endeavour is that the core meaning of exclusion for older people with dementia in care homes is loss of identity. Whilst claiming that loss of identity is key to understanding the exclusionary experience of people in this situation, the study has also acknowledged the creativity of capacity of participants affected by dementia to counter exclusionary processes.

Finally, in many ways this thesis has raised far more questions than it has been able to answer. Most notably, as some of the observations made in this study (like the one about tenure) have been made in relation to all participants living in a care home, there remains a huge question as to the *degree* exclusion processes are influenced by dementia related factors. It might be that this question can never be satisfactorily answered: this study has shown how individuals respond to different difficulties associated with cognitive impairment in different ways. An alternative question that those interested in dementia might ask is, what *other* barriers to inclusion does a person face besides (or in addition to) those associated with cognitive impairment. Perhaps the route to inclusion for this group of people involves the uncovering of these factors as well.

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# APPENDICES

## **Focus group participants**

### **Focus Group 1      Lulworth Court**

Ms. C aged 49. 2years in post. Previously SEN (M)  
Ms. A aged 57. 4 months in post.  
Ms. S aged 53. 4 years in post.  
Ms. T aged 60. Senior care worker for 4 years.  
Ms. P aged 25. 4 years in post.

### **Focus Group 2      Durlston Court.**

Ms. C aged 52. for 6 mths  
Ms.P aged 44. for 7 years 'always worked with old people for 20years'  
Ms.J age 52. Properiter/manager for 15 years. SRN. Dip HE in Geratology  
Ms.M aged 62. Care worker for 7 years  
Ms.D aged 36. Care worker for 3 years  
Ms. W aged 40. Care worker for 2 years. '24 years of caring'.  
Ms. T aged 41. Care worker for 3 years.  
Ms. H aged 53. Care worker (nights) for 5 years.  
Ms A aged 49. Care worker for 18 mths.

### **Focus Group 3      Encombe House**

Ms. D aged 23. Care worker for 2 weeks  
Ms E aged 39. Care worker for 6 months  
Ms K aged 30 Care worker for 3 years  
Ms B aged 52. Senior care worker for 4 years  
Ms. M aged 34. Care worker for 1 year.

## **Statements used to guide focus groups**

- 1 Having someone to represent your interests when important decisions are being made about your life
- 2 Getting up late most days
- 3 Eating food you like
- 4 Being able to go out whenever you wish
- 5 Wearing a call alarm so you can alert someone if you fall
- 6 Being able to make tea and toast whenever you like
- 7 Being helped to look after your things
- 8 Having your last meal of the day at 5pm
- 9 Being in control of your finances
- 10 Being able to choose when you have a bath
- 11 Knowing that people who care for you have been properly vetted
- 12 Having the facilities to hand-wash personal items
- 13 Being able to take painkillers whenever you need one
- 14 Having people talk over your head as if you are not there
- 15 Choosing where you would like to sit
- 16 Going out on an organised day trip
- 17 Choosing how to spend the day
- 18 Being able to lock your bedroom or flat door

v 'Empowering older people with dementia: balancing rights, risk and choice in residential settings'.

**Interview schedule: exploratory interviews involving participants with dementia.**

What sort of things do you like to do?

What do not like to do?

Is there anything you like to do but you can't?

What would you do if you didn't like something about living here?

What is important to you in your life at present?

Is there anything that worries you at all?

If yes: Is there anyone you like to talk to about your worries?

Is there anything you really like about living here?

Is there anything you don't like about living here?

Do ever need help from another person?

How do you let someone else know what you want?

Do you like to make choices about what you want to do?

Prompt: what to wear, buying new things, choosing what time to get up, when to have bath or go to bed; when to go out'  
What to eat, who to talk to, where to go.

\*\* it may be useful to use photographs/pictures as prompts to promote discussion about different activities.

This interview schedule is exploratory with the aim to find out what is important to the person with dementia. This will require sensitivity, careful listening and possibly finding out more about what the person enjoys etc. before the interview. This will require an open and exploratory approach. It may, for example, be useful to spend some time with the person to discuss their choices during a number of activities. Further, the use of photographs/pictures to promote discussion may be important.

## MAKING CHOICES IN EVERYDAY LIFE

### **Please Remember:**

It is entirely your decision to take part in the project and whether or not you choose to speak to us.

If you don't want to, that's alright. You don't have to give a reason.

If you want to stop the interview part way through, you are free to do so.

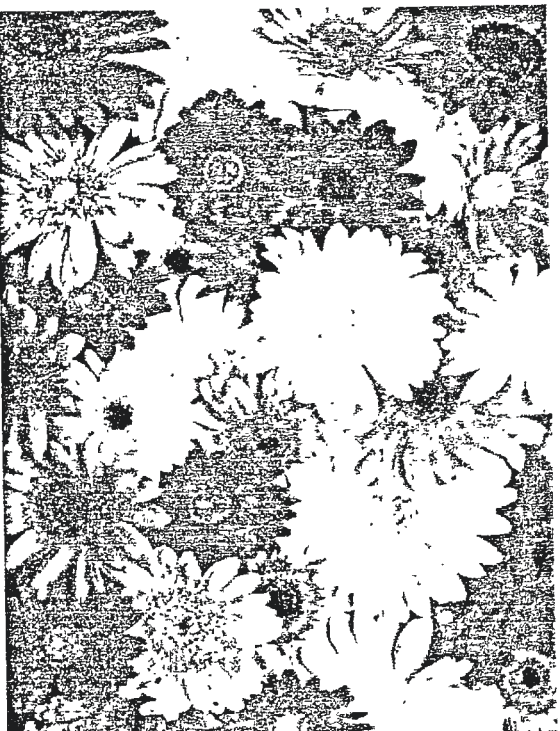
Whatever you decide, this will not affect the help you get here or anywhere else.

**Thank you very much.**

Wendy Martin and Ruth Bartlett  
School of Social Sciences and Law, Oxford Brookes  
University, Gipsy Lane Campus, Headington, Oxford.  
OX3 0BP. Tel: (01865) 484938/484941

*Applied and Qualitative  
Research Ethics Committee  
Study no: A00.006*

## MAKING CHOICES



## IN EVERYDAY LIFE

A project that looks at how people make choices

OXFORD  
**BROOKES**  
UNIVERSITY





*Applied and Qualitative Research Ethics  
Committee  
AQREC study number: A00.006*

OXFORD  
BROOKES  
UNIVERSITY



Date:

Gipsy Lane Campus  
Headington Oxford OX3 0BP

Head of School: Professor S McRae  
e-mail: [smcrae@brookes.ac.uk](mailto:smcrae@brookes.ac.uk)

Tel: 01865 483950/483750  
Fax: 01865 483937

Dear.....

We are a team of researchers working at Oxford Brookes University who are involved in a research project about the decisions and choices that are important to people who are aged 65 years and over. We are interested in talking with people about the way they plan their lives, the decisions they make and what choices are important to them in their everyday life. We feel that to hear things from your point of view will promote our understanding about the experiences that people have.

We would like to take this opportunity to invite you to take part in this research and would be grateful if you would consider meeting with us to talk about some aspects of this topic. An information sheet that explains more about the research is enclosed. Any information you give would, of course, be strictly confidential. If you agree to take part, you would be entirely free to discontinue at any time.

We would like to telephone you shortly to ask if you would be interested in hearing more about our research. However, if you would prefer not to be contacted, please return the attached form in the stamped addressed envelope provided.

With many thanks,

Yours sincerely,

Wendy Martin, Research Fellow. Tel: (01865) 484938.

Ruth Bartlett, Research Student. Tel: (01865) 484941.

*Applied and Qualitative Research Ethics  
Committee.  
AQREC study number: A00.006*

OXFORD  
BROOKES  
UNIVERSITY

CONSENT FORM



MAKING CHOICES IN EVERYDAY LIFE.

44 London Road  
Headington Oxford OX3 7PD

Tel: 01865 485275/8 (direct line)  
Reception Tel: 01865 485294  
Fax: 01865 485297

Professor Helen Bartlett BA MSc PhD RGN RHV  
Director

- 1) I confirm that I have read the information  
sheet for the above study and have had the  
opportunity to ask questions.

YES NO

☐☐

- 2) I understand that my participation is voluntary and I am free to  
withdraw at any time, without my present or future care being  
affected in any way

☐☐

- 3) I understand that parts of my medical notes may be looked at by  
responsible individuals where it is relevant to my taking part in  
the above project. I give permission for these individuals to  
have access to my notes

☐☐

- 4) I give permission for anonymous quotes to be used in any  
written and verbal presentations.

☐☐

- 5) I agree to take part in the above study

☐☐

Signed.....Date.....

Name (in block letters).....

Signed (witness).....Date.....

Name (in block letters).....

Signed (researcher).....Date.....

Name (in block letters).....